







## Including You



An information guide for hard of hearing people in Edinburgh and Lothian





#### Introduction

Losing your hearing can be a distressing experience. It can cut you off from friends and family, groups and social situations, and lead to feelings of isolation and even depression. Added to this, people around you may underestimate the sometimes devastating effects of acquired hearing loss.

"I was really struggling with my deafness—I stopped going out, and my marriage was suffering. No-one can give me my hearing back, but I've learned so much and am starting to cope much better."

However, the negative effects of acquired hearing loss are not inevitable, and with the right support and information, hard of hearing people can continue to enjoy a high quality of life. This guide is designed to provide you and your friends, family and supporters with a full range of advice and information to ensure that you continue to live life to the full. The guide was produced as part of Deaf Action's Including You Project, funded by The Big Lottery, to help improve the quality of life of hard of hearing people.

Throughout this guide, contact details for services printed in **bold italic** can be found in Section 8, Contact Details, alphabetical list.

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#### Section I

You think you have a hearing loss — what happens next?

#### Do you have a hearing loss?

It is estimated that over 105,000 people in Edinburgh and Lothian have a hearing loss\*. Are you one of them?

#### Do you:

- Miss parts of conversations when more than one person is talking?
- Have difficulty hearing voices, particularly children?
- Sometimes misunderstand what people are saying?
- Feel that people often seem to be mumbling or speaking quietly?
- Avoid social situations because you struggle to follow what is going on?

If this sounds familiar, you may want to discuss it with your GP. There are simple tests that he or she can do in the surgery to check if you do have a hearing loss. If appropriate, you can then be referred to your local NHS Audiology Department.

## What happens at an Audiology Department appointment?

There are three NHS **Audiology** departments in Lothian:

Lauriston Place, Edinburgh St John's Hospital, Livingston Roodlands Hospital, Haddington

Hearing tests take place in a sound-proof room, where you wear a set of headphones and tell the

audiologist when you hear different sounds. The audiologist is then able to determine your hearing loss, explain this to you, and carry out any other tests that may be needed.

Audiology staff can refer you to other services to help you to cope with your hearing loss, including counselling, speech and language therapy, a hearing therapist, a specialist tinnitus service or for balance assessments and rehabilitation. These services are based at the Audiology Department in Edinburgh at Lauriston Place, but can be accessed by people using Roodlands and St John's Audiology services.

You can be referred to Audiology by your GP, other health workers or a Deaf Action worker.

\*The National Study of Hearing, A. Davis and population estimates for Scotland



#### Getting your hearing aid

The Audiology team will make an appointment so you can be issued with your hearing aid(s). At the appointment, aids will be chosen for you according to your needs and requirements.

Hearing aids can be described as either analogue or digital, depending on the technology they use to process sound. In the past, the NHS issued mainly analogue hearing aids, but now you will be offered more modern digital hearing aids.

#### Analogue hearing aids

These electronic devices have a microphone to pick up sound, which is amplified and reproduced by a receiver that acts as a loudspeaker.

#### Digital hearing aids

These use a tiny computer to process sound, and can be programmed to suit your particular hearing loss and different listening conditions. If your hearing loss changes, they can be re-programmed to match changes in your hearing levels. Many digital aids use directional microphones which can help you hear sounds from in front of you more easily.

Your aid(s) can be programmed for different functions such as listening to music, automatic telephone adjustment, and for using induction loop systems. (See page 8 for more information about loop systems). These are just a few options available; your audiologist should discuss all of the options with you. He or she should discuss your hobbies and interests to help you to decide which settings would be best for your lifestyle; for example if you like

to attend concerts, then a music setting may help. You should get verbal and written instructions on how to use your hearing aid(s). The instructions should cover:

- The controls on the hearing aid
- Hearing aid maintenance
- Insertion of the hearing aid
- How to get batteries
- How to access the hearing aid repair service

It may take time for you to get used to wearing a hearing aid and the many different sounds you will hear. They will not restore your normal hearing and, unlike the human ear, are not able to filter out the sounds that you do not want to actively listen to — the aid will amplify all sounds, including background noise. It takes practice to learn how to ignore background noise, and is best to build up the time you spend using your hearing aid.

If you feel you have not received enough information about your hearing aid(s), it is important that you ask your audiologist for the information you need, to help you cope with the hearing aid as well as possible.

#### Review of hearing aids

A review will be offered if you have been fitted with a hearing aid for the first time. At the review appointment, your progress will be checked to ensure everything is as it should be and changes can be made if needed. Many people feel that there is a lot of information to take in when you first get your hearing aid(s), and reviews can be beneficial. A review may also be offered to existing hearing aid users if they are experiencing difficulties with their current aid. You can request a review at any time.

After you have had an aid for three years, you can request a re-assessment of your hearing directly from the audiology department.



#### **Audiology Repair Clinics**

From time to time you may have difficulties with your hearing aid – it may need re-tubing, for example. An appointment system for repairs is operated in each of the three NHS Audiology departments in Lothian, as well as a postal repair service. To use the postal repair service you need to send your hearing aid with a note of your name, address and what you think is wrong with your hearing aid, to your local audiology department. It is recommended that you use recorded delivery to send your aid.

Repair appointments are available:

Edinburgh, Lauriston Place Monday to Friday

West Lothian, St John's Hospital Monday to Friday

East Lothian, Roodlands Hospital, Haddington Thursday only

Repair appointments for any of the audiology departments should be made by phoning the Lauriston Place audiology department in Edinburgh as they operate a centralised booking system from there.

#### Hearing aid batteries

The normal life span of a hearing aid battery is only around 5 to 10 days, although this depends on the type of hearing aid you wear. You can get batteries for NHS hearing aids free of charge from audiology clinics, and from Deaf Action. When you get a hearing aid you are also given a battery book which details the size and type of battery

your hearing aid requires. You need to produce your battery book each time you need new batteries, and when you receive them, the book is signed by a staff member or volunteer at the hospital.

Any NHS hearing aid wearer can use the battery replacement service to get batteries from Audiology without making an appointment:

Edinburgh, Lauriston Place Monday to Friday mornings 9.30 - 12.30

Livingston, St John's Hospital Monday, Wednesday and Friday mornings 10.00 – 12.00

There is also a postal service for batteries and the details for this are printed on your battery book. When you post your battery book to an audiology department or to Deaf Action, your book will be signed and posted back to you with your batteries.

#### Cleaning your hearing aid

To get the best out of your hearing aid, it should be cleaned regularly. A slight blockage of ear wax or moisture in the tubing can reduce the sound quality.

The tubing and ear mould can be detached from the hearing aid in order to be cleaned. The mould and tubing can be put in warm water with a little mild detergent and cleaned with a cloth. They need to be completely dry before re-attaching to the hearing aid, so it may help to clean the mould and tubing last thing at night and leave it to dry overnight. At no point should the hearing aid itself be in contact with water.

If you do not feel comfortable detaching and reattaching the tubing, the mould can be cleaned daily with a wet wipe. Small cleaning instruments such as a brush or hook can be used to remove ear wax. You should receive cleaning instruments when you get issued with your hearing aid, or you can request them from your local Audiology department.

#### Cochlear Implants

A cochlear implant is a small, complex electronic device that can help to provide a sense of sound to a person who is profoundly deaf or has a severe hearing loss. The implant consists of an external portion that sits behind the ear and a second portion that is surgically placed under the skin.

An implant does not restore normal hearing. Instead, it can give a deaf person a useful representation of sounds in the environment and help that person to understand speech. Implants can be of use to someone who has had hearing and can remember sound, and may also be of use to some people who have never had hearing.

Refer to your GP or Audiologist for further information on cochlear implants, and for discussion on referral to an implant centre. There is an assessment process which you will be expected to go through prior to any decision being made on whether you are a suitable candidate for an implant.

Further information on cochlear implants and support groups can be found on the **Royal National Institute for Deaf People (RNID)** website, or by contacting the **RNID** office.

## Section 2 Home, family and friends

#### Communication

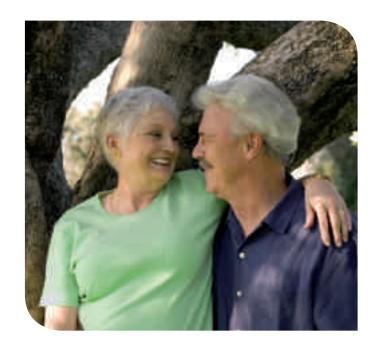
Communication is the single biggest hurdle faced by hard of hearing people in everyday life, and good communication in the home, with family and friends is crucial to maintaining your quality of life.

Hard of hearing people usually communicate using speech. The difficulties, of course, lie in trying to understand what other people say. For this reason, the actions of the speaker are central to making sure that you are able to participate in the conversation.

When talking to others, even though you might not be aware of it, you probably use a range of "tools" at your disposal – residual hearing, hearing aids, lipreading skills, concentration and sometimes a degree of guesswork. All of this takes a lot of energy, so you may find yourself getting tired when trying to lipread for longer periods.

This section provides advice on getting the most out of spoken communication. You may want to share photocopies of this section with family, friends, and all those who want to communicate with you.

"Good communication in the home, with family and friends is crucial to maintaining your quality of life"



## Guidelines for communicating with a hard of hearing person

- Get the attention of the hard of hearing person before you start to speak. If he or she is not looking at your face before you start speaking, they will not be able to use lipreading skills and may miss the topic of the conversation.
- Speak at your normal volume, and slightly more slowly. Do not shout or exaggerate your lip patterns as this will distort the message. Lack of clarity of speech sounds is often more of a problem than lack of volume. For example, people who have difficulty hearing consonant sounds (which are commonly lost with a high-frequency hearing loss) won't be helped by the speaker simply increasing in volume.
- Make sure that the hard of hearing person knows the topic of your conversation.
- Use natural gestures and facial expressions to help get your message across, such as nodding or shaking your head when appropriate.
- Do not turn away or cover your mouth when you are speaking. Many hard of hearing people use lipreading (even though they may not be aware of it) and need to see your face clearly.

- Make sure that your face is well-lit, and there is no bright light or window behind you, which can cast your face into shadow.
- Try to reduce background noise, or find a quieter room for your conversation. Soft furnishings will absorb noise and reduce echo.
- If the hard of hearing person does not hear what you have said, try rephrasing it.
- Write things down if need be, particularly important information like dates and times.
- Be patient, and remember that lipreading is difficult and tiring for a number of reasons; only 25-30 % of speech is lipreadable in ideal situations; some sounds are invisible on the lips, such as "h" as in "hill", "g" as in "goat" and "k" as in "kick"; some sounds look exactly the same as others, such as "m" "p" and "b", as in "man", "pan" and "ban".
- To get an idea of the difficulties of lipreading, try watching a newsreader on TV with the sound turned down!

#### Specialist Equipment for the home

Have any of these happened to you?

- You have missed a friend, caller or delivery because you did not hear the doorbell?
- You have given up on a telephone call because you could not hear the instructions on an automated telephone system?
- You have slept in because you did not hear the alarm clock?
- Someone has got annoyed with you because of the volume of your TV?
- Someone has said "never mind, it doesn't matter" when you have missed part of a conversation?

These experiences can be upsetting, and are all too common for people with a hearing loss. However, solutions can be found in the use of specialist equipment for hard of hearing people. Below is an overview of equipment and services that are available:

#### Induction Loop systems

These enable hard of hearing people to hear a spoken message directly via their hearing aid.

Loops are effective in reducing background noise and provide much more clarity. They can be used in conversation, to listen to televison, radio and music systems, as well as outside the home



in meetings, one-to-one consultations and at reception desks.

#### Listening devices

There is a variety of specialist equipment to help you talk to friends and family, listen to television, radio or enjoy music, including personal loop systems and systems that use infra red technology.

#### Alerting devices

These use lights or vibrating pads to alert you to a variety of things including doorbells, smoke detectors, baby alarms and alarm clocks.

#### **Telephones**

There is a variety of adapted telephones available, including those that use amplification, those that incorporate induction loops and text telephones (sometimes called Minicom).

#### SMS texting/Mobile phones

Some mobile phones can work with your hearing aids on the loop setting and/or have increased amplification and powerful speakerphone functions. There are also neckloops and ear hooks that can be used with mobile phones to enable you to hear on a mobile phone. Texting enables you to type and receive short messages on your mobile phone, which can be very effective in enabling you to keep in touch with friends and family.

**Text Relay** is a national telephone relay service for deaf and speech impaired people (formerly known as RNID Type Talk). If you are using a textphone or you are calling someone from a standard telephone and think the person at the other end may have a textphone, Text Relay will connect you. It is a fully automated service so, when required, relay operators provide a text-to-voice and voice-to-text translation service.

If you are deaf and use a textphone to call someone using a standard voice telephone, dial 18001 followed by the full dialing code and telephone number. This will put you in touch with an operator who will relay your typed message to the person you are calling. If you are using a standard voice telephone, and expect that the person answering uses a textphone, dial 18002 followed by the full dialing code and telephone number. This will put you in touch with an operator who will use a textphone to type your spoken message to the deaf person.

Calls are charged at your telecommunications provider's standard rates. You may also be able to get a refund from your provider for the text part of your call. All calls are confidential and the service operates 24 hours every day.

#### Specialist Equipment providers

#### Deaf Action's Specialist Equipment Service,

in partnership with local authorities, provides a range of specialist equipment, often loaned free of charge to hard of hearing people living in East, West and Midlothian, and in Edinburgh. You can make an appointment to visit our Albany Street office for an assessment of your needs, and to

see and try out equipment to ensure that you choose the most suitable product for you. If you are unable to visit our office, we can arrange a home visit to assess your needs. We also offer a free follow-up advice and repair service.

Deaf Action is also a registered centre for British Telecom's 'Try Before You Buy' scheme. This allows you to try out a range of amplified BT telephones to find the right one for you.

For a specialist equipment assessment appointment, or to "try before you buy", contact **Deaf Action's Specialist Equipment Service**.

Some equipment is available for purchase, such as doorbells and alarm clocks, from stores like B&Q and Argos, or from specialist suppliers including **Deaf Action's Specialist Equipment Service**, **Connevans** and **RNID Solutions**, who provide catalogues and websites.

#### **Assistance Dogs**

Some people find that hearing dogs provide great benefit in terms of maintaining independence and providing companionship, whether in the home or out in public. **Hearing Dogs for Deaf People** train dogs to alert deaf people to specific sounds, such as the alarm clock, doorbell, telephone or smoke alarm. You can apply for a hearing dog if you are severely hard of hearing or profoundly deaf. To apply for a dog, you need to be able to provide proper exercise, grooming, food and medical care (help may be given if this is difficult for you), and be willing to build a working partnership with the dog.

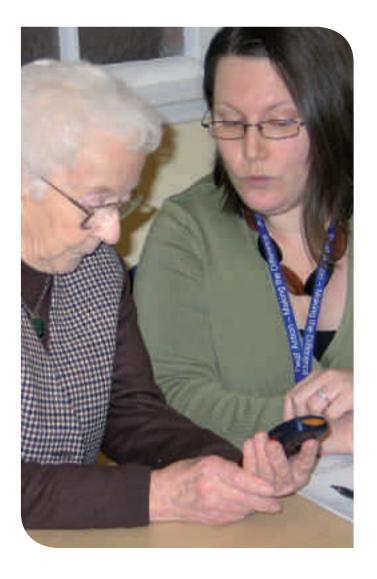
#### Social Work

Each of the local authorities in Edinburgh and Lothian commissions **Deaf Action's Social Work Service** to provide a specialist service for people with a hearing loss. Social Workers provide assessment and support, as well as a range of practical advice including help with benefits. We offer a duty service in Edinburgh, West Lothian, and East Lothian, where you can drop in without an appointment for advice and information, or to discuss a problem. Contact the team for details of this service.

Support at home

**Deaf Action's Support Services** assist people with a hearing loss who also have other support needs, including visual impairment, physical or learning disability. The service enables individuals to live in their own homes with tailored support to meet their needs, including 24-hour on-call support at our residential facility at Slateford Green in Edinburgh, and a visiting outreach service. All our workers are trained in specialist communication skills for people with a hearing loss.

"our Social Workers have specialist communication skills, and are qualified to practise in all aspects of work where deaf people may need support"



#### Information, Advice and Guidance

**Deaf Action's Including You Project** provides information, advice and guidance on a range of topics and issues to improve your quality of life. Project workers have produced this guide to ensure that you have access to the full range of available services and information for hard of hearing people in Edinburgh and Lothian. Workers also provide:

- One-to-one advice, in your own home if necessary
- · Advice on maintaining your hearing aids
- Welfare benefits checks
- Information on other available services
- Support in the workplace, and advice to employers
- Courses on topics such as mobile phone texting, building confidence, and helping family and friends communicate with you more effectively

Hearing Concern LINK Scotland works with people with an acquired hearing loss, including those who are deafened, that is, have become profoundly deaf. The organisation can provide specially trained Outreach Volunteers who can talk to you about deafness and give you useful information about how to cope and where to get help. The Outreach Volunteer team consists of both deafened volunteers and their partners, as deafness can affect the whole of family life.

"I had my phone for ages but didn't know how to use it. I'm now regularly texting my grandchildren!"

**Edinburgh Hard of Hearing Club** meets each Tuesday at 2.00pm from October to April at Deaf Action's Head office in Edinburgh. The Club is managed by an elected committee of hard of hearing people, who arrange an interesting programme of events with invited speakers and regular lipreading classes.

The **Scottish Council on Deafness (SCoD)** is a Scotland-wide umbrella body that works with many deaf organisations across the country. As part of their work to provide comprehensive information to deaf people, they publish regular newsletters and bulletins, which aim to keep deaf people up-to-date with local and national developments. Contact SCoD to join their information mailing list, or access bulletins online at **www.scod.org.uk/bulletins** 

#### **Benefits**

You may be eligible for a range of welfare benefits such as Disability Living Allowance, Attendance Allowance, Pension Credit, Working Tax Credit and Child Tax Credit. If you need further information about benefits, **Deaf Action's Including You Project** Worker can assist you. They can give you specific information on benefits available, help you make an application for a benefit and help you to challenge a decision.

### Section 3 Work

Whether you have been deaf for a long time, or you lost your hearing more recently, coping with hearing loss in the workplace can present particular challenges. You might fear that you will not be able to carry out the tasks that you used to, for example using the telephone, or taking part in meetings, and this can leave you feeling vulnerable.

In many cases, difficulties arise because employers do not know what their responsibilities are, what type of support is available, or where to get advice. In fact, there is a range of support available to workers and employers, to enable you to continue successfully in your job.

#### The legislative context

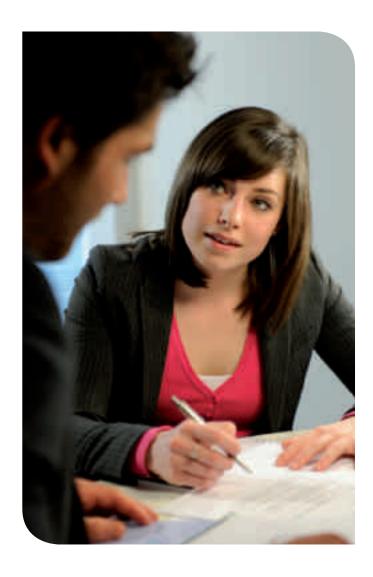
The Disability Discrimination Act (1995) provides protection in the workplace against discrimination on the grounds of deafness, where your hearing loss can be described as 'a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities'. The Act says that it is unlawful for an employer to discriminate against you:

- in the terms of employment offered
- in the opportunities for promotion, transfer, training or receiving any other benefit
- by refusing to offer you, or deliberately not offering, any such opportunity; or
- by dismissing you, or subjecting you to any other negative treatment

If you feel you have suffered discrimination on the grounds of your hearing loss, you can contact the **Equality and Human Rights Commission**, who operate a helpline and provide a range of advice and support.

Organisations providing support Access to Work is a government-funded service that can help if your hearing loss affects the way you do your job. The service gives you and your employer advice and support with extra costs which may arise because of your needs. Your employer may be required to contribute to the cost of support. Access to Work may pay towards equipment, adapting premises to meet your needs or providing a support worker. For someone with a hearing loss, this could mean, for example, providing an adapted telephone, or listening devices for meetings. It could mean installing a loop system in your workplace, or providing a communication support worker. More details about communication support and how it can be used in the workplace are provided on page 14. These types of support can be crucial to how you cope at work, and it is your right to have access to them.

**Deaf Action's Including You Project** Worker can meet you to discuss any concerns about how your hearing loss affects your work, and help you to overcome any problems. The worker can liaise with your employer and work colleagues if appropriate, and help provide practical solutions, to help you get the support you are entitled to.



#### Communication Support

There is a variety of communication support available to assist with communication between deaf and hearing people. This can be of great benefit to people in the workplace, for example in meetings, supervision and training. All professional communication support staff operate a strict code of practice, including confidentiality.

In the workplace, communication support can be funded by Access to Work (see page 13). For other settings such as health or council appointments, it is normally the responsibility of the service provider to pay for communication support.

Deaf Action is the largest provider of communication support in Edinburgh and Lothian. For advice on the type of support that is best for you, and to book, contact **Deaf Actions Communication Support Service**.

Below you will find information on the types of communication support that may be of use to people with an acquired hearing loss. Information on communication support for people who use British Sign Language, or are deafblind can be found at **www.deafaction.org** 



#### Lipspeakers

- are used by people who use lipreading as their main method of communication
- are trained to reproduce the shape, flow, rhythm, stress and phrasing of speech used by the speaker
- convey a speaker's message to a lipreader without using their voice
- use facial expression, gesture, and if requested, fingerspelling to aid in the lipreader's understanding

#### Notetakers - electronic and manual

- write or type everything that is said during proceedings
- aim to ensure as full a coverage of information as possible (in negotiation with the wishes of the deaf person)
- are trained in speed and clarity
- may use a laptop which is connected to another laptop, on which the deaf person reads the transcription
- may use a laptop which is connected to a large screen in a conference / meeting setting, from which many deaf people in an audience can read the transcription

#### **Speedtext operators**

- use a laptop which is connected to another laptop, on which the deaf person reads the transcription
- use specialist computer software
- may summarise what is being said

#### **Deaf Awareness Training**

Sometimes specialist Deaf Awareness training can be helpful in the workplace, to enable colleagues to learn what they can do to ensure that you are included, like anyone else in your workplace. This could involve training on topics such as communication tactics and specialist equipment. **Deaf Action's Training Team** can provide this service, tailoring the training to the particular work environment. In some circumstances, **Access to Work** may fund such training.

## Section 4 Learning

#### Mainstream learning providers

There is a wealth of adult learning providers who offer a broad range of courses including evening and leisure courses, vocational training, further and higher education. Each of these providers has a responsibility, under the Disability Discrimination Act (1995), to help meet your needs to access their courses, and to make 'reasonable adjustments' to their provision in order for you to participate. This might include provision of specialist equipment in the learning environment, such as a loop system, or communication support. See page 8 for information on equipment and page 14 for communication support that may benefit you. Before you enroll on a mainstream course, you should contact the learning provider to let them know your needs and allow time for them to make the necessary arrangements. Many learning providers, including colleges and universities, have dedicated staff to assess and make arrangements to meet your needs. They may have a variety of job titles such as Access Officer or Disability Adviser.

#### Paying for your learning

Grants may be awarded by the **Student Awards** Agency for Scotland to help meet the extra course costs you can face as a direct result of a disability, including hearing loss. To apply for financial help through Disabled Students' Allowances (DSAs), both you and your chosen course must meet some conditions. You will need to check with the education provider that your course is eligible before making your application. Eligible full-time, part-time and postgraduate students can apply for DSAs. The amount you get does not depend on your household income. DSAs are paid on top of the standard student finance package, and do not have to be paid back. The allowances can help pay for specialist support you need for studying - for example, assistive listening devices and non-medical helpers, such as a notetaker. You can apply if you are doing a full time course that lasts at least one year (including a distance-learning course) or a part-time course that lasts at least one year and does not take more than twice as long to complete as an equivalent full time course.

You may also be eligible for financial support to assist in paying for your class through an Individual Learning Account (ILA). **ILA Scotland** is a Scottish Government scheme that helps you pay for learning that you can do at a time, place, pace and in a way to suit you. It is for people who have an income of £22,000 a year or less, or who are on benefits. If you are 16 or over, you could get up to £500 towards the cost of learning with a learner account from ILA Scotland.



#### Specialist learning providers

#### **Deaf Action's Learning Centre**

We run a range of "deaf friendly" classes for adult learners from our head office in Edinburgh. We have specialist courses for hard of hearing people including Computing for beginners and improvers, Art, Patchwork and Quilting, and British Sign Language. Our classes are taught by tutors who have a hearing loss themselves, or are trained in appropriate communication tactics, and your fellow learners will also be hard of hearing. We offer both unaccredited courses, and courses accredited by the Scottish Qualifications Authority (SQA).

#### Lipreading Classes

Some people, both deaf and hearing, have unrealistic expectations about lipreading. In fact, lipreading is not an "exact science" that you can learn in order to overcome all your communication difficulties. Rather, it is a set of skills and strategies that you can use to enhance your ability to understand what others are saying. Bear in mind some of the points on page 7:

- only 25-30 % of speech is lip readable in ideal situations
- some sounds are invisible on the lips, such as "h" as in "hill", "g" as in "goat" and "k"as in "kick"
- some sounds look exactly the same as others, such as "m" "p" and "b", as in "man", "pan" and "ban"

That said, improving your lipreading skills can have a dramatic impact on your communication. **Lipreading classes** teach you to make the most of your lipreading skills and are also an opportunity to learn about different services and organisations. Another vital aspect of classes is the opportunity to meet other people who have a hearing loss and share experiences and coping strategies. Classes tend to be small in size and often have guest speakers to share information with you on hearing loss and coping strategies. The class usually lasts for about two hours and allows you to have fun while learning, and to discuss issues around your hearing loss with others who understand.

Classes are run by your local council, usually through their adult education program. The classes are free of charge and you may be offered a place in a class for up to two years.

Deaf Action's Training Team offers SQA accredited courses in British Sign Language (BSL) and Deaf Awareness, as well as tailored courses to meet a group or organisation's specific requirements. While most of our learners are hearing people, hard of hearing learners are also welcome. Some people who are losing their hearing are keen to learn Sign Language to help with everyday communication. Bear in mind that, as well as learning the language yourself, the people around you will need to learn it too, in order for you to benefit. Deaf Action sometimes organises BSL courses specifically for hard of hearing people — contact Deaf Action's Learning Centre for more information.

Hearing Concern LINK Scotland runs selfmanagement courses for people with an acquired hearing loss, and their spouses or supporters. The courses aim to help people adapt to their new circumstances, and equip them with skills and information to improve their quality of life.

**Deaf Action's Including You Project** offers specialist courses which can help improve the quality of life of hard of hearing people. Workers can offer courses on topics such as how to maintain your hearing aid, how to cope confidently with your hearing loss and how to use mobile phones to send and receive text messages.

"I love my course, and I get a lot out of meeting others in the same situation"



## Section 5 Health

Section I provides more information about NHS services relating to Audiology and your hearing loss. This section provides more general information about health services for people with a hearing loss and how to access them.

#### Barriers to healthcare

Visiting the GP or other health appointments can present particular challenges to hard of hearing people. Research by the RNID (A Simple Cure? 2004) showed that:

- 28% of deaf and hard of hearing people found it difficult to contact their GP surgery to get an appointment because of their hearing loss
- 15% of deaf and hard of hearing people said they avoid going to see their GP because of communication problems
- 24% of patients had missed an appointment because of poor communication, such as not being able to hear staff calling out their name
- 42% of deaf and hard of hearing people who had visited hospital (non emergency) had found it difficult to communicate with NHS staff
- 35% of deaf and hard of hearing people had been left unclear about their condition because of communication problems with their GP or nurse

Deaf Action's own survey and report, "Speaking Up" (2008), found that hard of hearing people continue to struggle with communication as a result of poor deaf awareness on the part of service providers.

"My doctor keeps forgetting I have a hearing loss. He talks and doesn't move his lips"

"(They) tend to speak slowly to begin and then go off at a rate. I usually end up agreeing with them — it's easier".

"I tell my dentist I have to lipread but he still talks to me with his mask on. I can hear a sound but I don't know what he is saying. It makes me quite cross"

Experiences such as these can have a major, negative impact on confidence and independence, and can reduce effective access to healthcare.



#### Solutions

Health services including hospitals, GPs, dentists and opticians have a statutory duty to enable you to access their services. This could mean provision of communication support such as a lipspeaker or notetaker for appointments. When making an appointment with a health professional, you can ask staff to book a lipspeaker or notetaker to enable you to communicate effectively with the practitioner. In Edinburgh and West Lothian, this free service is provided by the *Interpreting and Translation Service (ITS)* and in East and Midlothian it is provided by *Deaf Action's Communication Support Service*. See page 14 for more information on communication support available to you.

Many healthcare settings now have induction loops fitted at the reception area, and sometimes in consulting rooms. It is very common, however, that these are not working, not charged, or the

reception staff are not aware of how to use them. If that is the case, you can suggest they contact **Deaf Action's Specialist Equipment Service**, or the loop provider for advice on how to operate the loop.

You may prefer to ask health professionals to make sure they write down important information for you at your appointment, such as details of how to take medication. Many health professionals may be unaware of how best to communicate with you, and may appreciate if you provide a copy of the communication guidelines on page 7. Some hard of hearing people find it helpful to tell GP practice staff to mark your file with a note or sticker indicating that you are hard of hearing. This can ensure that instead of simply calling your name at an appointment, for example, they approach you personally to tell you when it is time for your appointment.

## Specialist health services for deaf people

#### **Lothian Deaf Counselling Service**

This service provides free one-to-one counselling to adults with a hearing loss in Edinburgh and Lothian. A personal loop system and/or communication in written English are available for people who are hard of hearing. Counselling is a confidential and supportive relationship with someone who is trained and experienced in helping people cope with difficulties in their lives. You might find counselling helpful if:

- you feel depressed, anxious or upset
- have problems with family and/or friends
- someone close to you has died
- you are unhappy at work/college
- you want to make changes to your life

You can be referred to this service by a Doctor, Social Worker, Community Mental Health Nurse, Audiologist, or Deaf Action worker.

#### Lothian Deaf Community Mental Health

**Service** is Scotland's first community mental health service for deaf people who have mental health, psychological or emotional needs that make everyday living more difficult. The service has been developed as a partnership between NHS Lothian and Deaf Action.

For people registered with a GP within the NHS Lothian area, the service offers:

- Assessment
- A broad range of interventions promoting recovery and social inclusion
- Therapeutic group work
- Advice and support to family and carers

Referral can be made by GPs, psychiatrists, other medical staff, mental health staff, social workers or Deaf Action staff.



# Section 6 Police and emergencies

## Accessible emergency contacts and related information

Getting the help you need in an emergency can be a real concern for people who are hard of hearing because of difficulties using the traditional methods of communication. You might find it useful to save the details below, such as mobile phone numbers in your phone, so you can easily access them in case of emergency.

#### Text Relay

This is a national telephone relay service for people with a hearing loss who use a textphone (formerly known as RNID Type Talk). See page 9 for more details of this service. By dialing **18000** on its own, and using your textphone, you will be put in direct contact with the emergency services.

#### Lothian and Borders Police SMS Service

This service allows deaf people who are registered with the service to use their mobile phones to contact the police, by texting **07717 993262**. You need to complete a registration form which can be downloaded from the police website **www.lbp.police.uk/deaf** or from a police station. You can also get a form from Deaf Action's main office.

When you are registered, you can use the number to contact the police. Send:

- Your name
- Where you are
- Where the incident is taking place
- What is happening (brief details)

A text message will be sent back to your mobile phone, confirming that the police have received your text.

#### **Emergency SMS 999 Service**

This service, which is being piloted at time of publication, allows deaf people across the UK to send an SMS text message to the UK 999 service where it will be passed to the police, ambulance, fire and rescue, or coastguard. If this trial is a success, a permanent emergency SMS 999 service will be launched.

Like the Lothian and Borders Police texting service, you need to register your mobile phone before using the trial emergency SMS service. Do this by going to **www.emergencysms.org.uk** 

#### Remote Reporting

This service allows a victim of a crime to report the matter to a third party agency that in turn forwards the report to the police. Deaf Action is a registered Remote Reporting Centre, where you can talk to our staff who will offer support and advice, and act as a link between you and the police.

Many deaf people find this service useful because they are reluctant to approach the police directly, not least because of communication barriers with police staff. To use this service, contact **Deaf Action's** main office.



## Section 7 Hearing loss and related conditions

#### How we hear

During normal hearing, sound goes into the outer ear, passes through the middle ear where the auditory bones, the ossicles, stretch across the middle ear cavity to conduct sound from the eardrum to the inner ear. The sound is then processed by the inner ear before being sent as signals to your brain.

When sound waves enter the fluid of the cochlea in the inner ear, they move tiny hair cells, which then send electrical messages to the auditory nerve. Different frequencies of sound are picked up by different hair cells, depending where in the spiral tube they are located. The nerve passes impulses to your brain, which recognises them as different sounds such as speech, music, footsteps, etc.

#### About acquired hearing loss

Acquired hearing loss is a very common condition, affecting an estimated one in six of people at some point in their lives. In Edinburgh and Lothian alone, it is estimated that there are over 105,000 people with a hearing loss. The incidence of acquired hearing loss increases with age, to the extent that three quarters of people over the age of seventy have a hearing loss.

### Conductive hearing loss - outer or middle ear problems

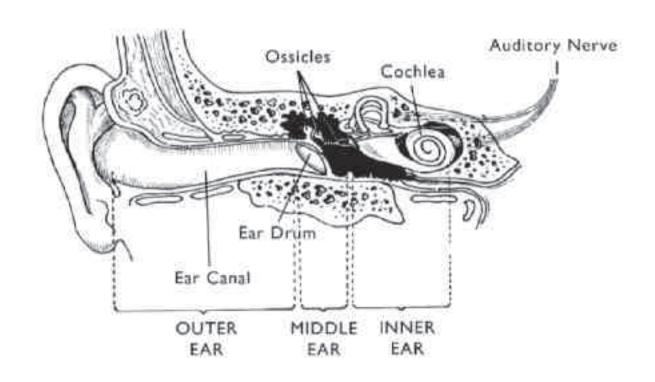
Conductive hearing loss can be caused by sound being unable to pass through the outer or middle ear. This may be because of:

- Restricted movement of the auditory bones in the middle ear, known as otosclerosis
- Hole in the ear drum, known as perforation
- Ear wax
- Glue ear most commonly found in children

### Sensorineural hearing loss - inner ear problems

This is caused by damage to the tiny hair cells within the cochlea in the inner ear. Sensorineural hearing loss is the most common cause of acquired hearing loss. Damage can be caused by a number of factors including:

- The ageing process
- Exposure to loud noise
- Traumatic injury such as a fall or a head injury
- Illness or infections such as measles, mumps or meningitis
- Ototoxic effects, that is, reactions to drugs or medications



#### Some other conditions

#### **Tinnitus**

Tinnitus is experienced as noises inside the head that do not come from an external source, and often sound like buzzing, whistling, hissing or ringing, or sometimes as songs or tunes. If the cochlea hair cells are damaged or overstimulated, this can cause irregular nerve signals to the brain, which perceives it as noise inside the head. Although not life-threatening, it can be extremely upsetting, and is a very common condition, thought to affect about one in ten. About one in a hundred people report that they have had tinnitus that severely affects their quality of life (RNID).

Tinnitus can affect you whether you have a hearing loss or not. It can be caused by hearing disorders related to ageing or exposure to loud noise, and can be affected by emotional upset, injury, illness, and the side effects of some drugs.

There is a range of treatments and therapies that can be useful for people with tinnitus. The audiology department of NHS Lothian in Edinburgh has a specialist tinnitus service. You can be referred to the service by an Ear, Nose and Throat (ENT) specialist, a GP or your Audiologist. An assessment will be carried out and you will be advised of the best treatment and management of your condition.

The **British Tinnitus Association** can offer advice and support on the condition.

### Edinburgh and South East Scotland Tinnitus Group

This group organises regular meetings and support groups for people with tinnitus. They provide an opportunity to meet with and speak to people who understand the problems faced by people who have tinnitus. Support groups meet regularly throughout the year and organise speakers to give information on a range of help and support.

Ménière's Disease is a disease of the inner ear. It is a long term, progressive disease which damages both the balance and hearing parts of the inner ear. The main symptoms of the disease are vertigo, tinnitus and hearing loss. Your GP can diagnose and offer management strategies for Ménière's disease, and may refer you to an Ear, Nose and Throat (ENT) specialist for help to manage your symptoms. The *Ménière's*Society is a charitable organisation offering advice and information on Ménière's Disease. Information on treatment and coping strategies can be found on their website.

Hyperacusis is the name given to increased sensitivity to normal level sounds. People with hyperacusis may feel pain or discomfort when hearing sounds that most people are able to tolerate. The causes of the condition are not yet well understood, but it is thought that the problems arise from faulty processing of sound in the inner ear. If you do not have an NHS hearing aid, you can consult your GP for advice and referral to an ENT specialist. Existing NHS hearing aid users can discuss this issue with the Audiology team. The Lead Hyperacusis Specialist can arrange an appointment to discuss your condition and advise on the most appropriate management options.

#### Balance assessments and rehabilitation

If you are experiencing dizziness or feel off-balance and are concerned about it, speak to your GP in the first instance. He or she may refer you to Edinburgh Audiology's balance unit for diagnosis of various balance disorders. Sometimes you will be advised to bring someone with you or to leave your car at home as some tests can stimulate the balance disorder:

#### **Deafblindness**

People are regarded as deafblind if they have a severe degree of combined visual and auditory loss resulting in difficulties with communication, mobility and information. Most deafblind people are over the age of 60 and have a dual sensory loss due to ageing. **Deafblind Scotland** can provide a range of specialist support including project work and a Guide/Communicator service. Guide/Communicators relay information, facilitate communication with others and ensure that the deafblind person is able to get about safely. They enable deafblind people to make informed decisions by ensuring information (spoken, nonverbal, written and environmental) is delivered using the deafblind person's preferred communication method, such as British Sign Language, Deafblind Manual or hands-on-signing. The service may be funded by your local Social Work department, following an assessment of your needs, which can be carried out by Deafblind Scotland staff. If you have both a hearing and sight loss, you can become a member of Deafblind Scotland, and keep up-to-date with relevant news and information.

**Sense Scotland** provides services for children and adults who have communication support,



information, learning and mobility needs because of deafblindness, sensory impairment, learning or physical disabilities. By working closely with people, often on a one-to-one basis, the organisation aims to find out what their aspirations are and how they want to live their lives.

#### Deafness and dementia

Both deafness and dementia are conditions that become more prevalent with age. Some people who develop dementia will have been deaf from an early age, but for others, both deafness and dementia will have developed in later life. The difficulties which are part of dementia are made much worse when the person cannot hear properly. The response of others to this situation will have a huge effect on how people with deafness and dementia feel and what they are able to do.

In 2004 Deaf Action, in partnership with the University of Stirling Dementia Services Development Centre, carried out research and produced a report on deafness and dementia. The report is available to view via **www.deafaction.org**, or you can get a copy by contacting our head office. More information on dementia can be found by contacting **Alzheimer Scotland**, who have a free 24 hour helpline **0808 808 3000** (Text Relay callers can use the **18001** prefix).

# Section 8 Contact Details – alphabetical list

Below is a list of services and contacts that are mentioned in this guide. We have provided as many accessible contact details as possible. Where only a voice phone number is provided, textphone users can use the Text Relay prefix 18001. More details on how this service works are provided on page 24.

#### Access to Work

Jobcentre Plus Access to Work Operational Support Unit Anniesland JCP Baird Street

Glasgow G90 8AN

Tel 0141 950 5327 Text 0845 602 5850 Fax 0141 950 5265

Email

atwosu.glasgow@jobcentreplus.gsi.gov.uk

#### Alzheimer Scotland

22 Drumsheugh Gardens Edinburgh EH3 7RN

Phone 0131 243 1453 Fax 0131 243 1450

Email alzheimer@alzscot.org

24 hour Dementia Helpline Freephone 0808 808 3000

#### Audiology

#### Edinburgh Audiology Department

Level I Lauriston Building 39 Lauriston Place Edinburgh EH3 9EN

Tel 0131 536 3737 Fax 0131 536 3779

#### West Lothian Audiology Department

St John's Hospital Howden Road West Howden Livingston West Lothian EH54 6PP

Tel\* 0131 536 3737

#### East Lothian Audiology Department

Roodlands Hospital Hospital Road Haddington East Lothian EH41 3PF

Tel\* 0131 536 3737

\*Appointments for Roodlands and St John's need to be made via the Lauriston buildings number; they have a centralised booking system for all appointments.

#### **British Tinnitus Association**

Ground Floor, Unit 5 Acorn Business Park Woodseats Close Sheffield S8 0TB

Freephone Helpline 0800 018 0527

Text 0114 258 5694
Fax 0114 258 2279
Email info@tinnitus.org.uk
Web www.tinnitus.org.uk

#### Connevans

54 Albert Road North Reigate Surrey RH2 9YR

Tel 01737 247 571
Text 01737 243 134
Fax 01737 223 475

Email info@connevans.com
Web www.connevans.co.uk

### Deaf Action Main contact details

49 Albany Street Edinburgh EH I 3QY

Tel 0131 556 3128 Text 0131 557 0419 Fax 0131 557 8283 SMS 07775 620 757

Email admin@deafaction.org

Videophone 82.71.100.121

Web www.deafaction.org

#### Deaf Action's Communication Support Service

Ia Millburn Road Inverness IV2 3PX

Freephone 0800 014 1401

Email bookings@deafaction.org

SMS 07791 800 064 Fax 01463 250 749 Tel/Text 01463 250 204

#### Deaf Action's Including You Project

49 Albany Street Edinburgh EHT 3QY

Tel 0131 550 0995
Text 0131 557 0419
Fax 0131 557 8283
SMS 07792 941 629
Videophone 82.71.100.121

Email debbie.gibson@deafaction.org

#### Deaf Action's Learning Centre

49 Albany Street Edinburgh EHT 3QY

Tel 0131 556 3128
Text 0131 557 0419
Fax 0131 557 8283
SMS 07775 620 757
Videophone 82.71.100.121

Email emma.mcgowan@deafaction.org

#### Deaf Action's Social Work Service

49 Albany Street Edinburgh EH I 3QY

Tel 0131 556 3128
Text 0131 557 0419
Fax 0131 557 8283
SMS 07775 620 757
Videophone 82.71.100.121

Email socialcare@deafaction.org

#### Deaf Action's Specialist Equipment Service

49 Albany Street Edinburgh EH I 3QY

Tel 0131 556 3128
Text 0131 557 0419
Fax 0131 557 8283
SMS 07775 620 757
Videophone 82.71.100.121

Email

specialistequipment@deafaction.org

#### **Deaf Action Support Services**

7/2 Slateford Green Edinburgh EH14 INE

Tel 0131 442 6924 Fax 0131 443 9858 SMS 07825 204 073

#### Outreach visiting service

Tel 0131 442 6900

Email slatefordgreen@deafaction.org

#### Deaf Action's Training Team

49 Albany Street Edinburgh EH I 3QY

Tel 0131 556 3128
Text 0131 557 0419
Fax 0131 557 8283
SMS 07775 620 757
Videophone 82.71.100.121

Email learn@deafaction.org

#### **Deafblind Scotland**

21 Alexandra Avenue

Lenzie

Glasgow G66 5BG

Tel/Text 0141 777 6111 Fax 0141 775 3311 Helpline 0800 132 320

Email info@deafblindsscotland.org.uk Web www.deafblindscotland.org.uk

## Edinburgh and South East Scotland Tinnitus Group

Tel 01324 485 617

#### Edinburgh Hard of Hearing Club

c/o Deaf Action 49 Albany Street Edinburgh EHT 3QY

Tel 0131 556 3128 Text 0131 557 0419 Fax 0131 557 8283 Mob/SMS 07775 620 757

#### **Emergency SMS 999 Service**

Register your mobile phone at www.emergencysms.org.uk.

You can then text 999 in an emergency.

## Equality and Human Rights Commission (EHRC)

The Optima Building 58 Robertson Street Glasgow G2 8DU

Tel 0141 228 5910 Fax 0141 228 5912

Email

scotland@equalityhumanrights.com

Web

www.equalityhumanrights.com/scotland

EHRC also operate a helpline for information and guidance on discrimination and human rights issues:

Helpline 0845 604 5510 Text 0845 604 5520 Fax 0845 604 5530

Opening hours: Monday - Friday 8:00 am-6:00 pm

#### Hearing Concern LINK Scotland

The Eric Liddell Centre 15 Morningside Road Edinburgh EH10 4DP

Tel 0131 447 9420

Email Scotland@hearingconcernlink.org
Web www.hearingconcernlink.org

Hearing Concern LINK also have a helpdesk that people can contact during office hours.

Tel 01323 638 230 Text 01323 739998 Fax 01323 642 968 Mob/SMS 07526 123 255

Email helpdesk@hearingconcernlink.org

#### Hearing Dogs for Deaf People

The Grange
Wycombe Road
Saunderton
Princes Risborough
Bucks HP27 9NS

Tel 01844 348 100 Fax 01844 348 101

Email info@hearing-dogs.co.uk
Web www.hearing-dogs.co.uk

#### **ILA Scotland**

PO Box 26833 Glasgow G2 9AN

Tel 0808 100 1090

Email enquiries@ilascotland.org.uk

#### Interpreting and Translation Service (ITS)

Central Library George IV Bridge Edinburgh EHT TEG

Tel 0131 242 8181 Fax 0131 242 8009

E-mail its@edinburgh.gov.uk

#### Lipreading classes

#### Edinburgh:

South Bridge Resource Centre

Infirmary Street Edinburgh EH LIT

Tel 0131 558 3545 Fax 0131 558 9355

Email aileen.paterson@ea.edin.sch.uk

Web www.lipreading.edin.org

#### West Lothian:

Adult Learning Centre 6-10 Glasgow Road Bathgate EH48 2AA

Tel 0800 731 1831 or 01506 776 333

Fax 01506 776 323

Email

Janice.davidson@westlothian.gov.uk

Classes run in Bathgate and Livingston

#### East Lothian:

East Lothian Council 9-11 Lodge Street Haddington EH41 3DX

Tel 01620 827 492

or 01620 828 6779

Email ccrawford@eastlothian.gov.uk

Classes run in Dunbar, North Berwick, Haddington and Musselburgh

#### Midlothian:

MALANI

(Midlothian Adult Literacy and Numeracy Initiative)

3 Eskdale Court

Dalkeith

Midlothian EH22 IAG

Tel 0131 270 8900

Email malani@midlothian.gov.uk

Classes run in Dalkeith and Penicuik

#### Lothian and Borders Police SMS service

Register at www.lbp.police.uk/deaf. You can then text 07717 993262 in an emergency.

## Lothian Deaf Community Mental Health Service

49 Albany Street Edinburgh EH I 3QY

Tel 0131 556 3128 Text 0131 557 0419 Fax 0131 557 8283 SMS 07775 620 757

Email admin@deafaction.org

Videophone 82.71.100.121

Web www.deafaction.org

#### Lothian Deaf Counselling Service

Lifeskills Health New Douglas Park Cadzow Avenue Hamilton MI 3 0FT

Tel 0800 804 7462 Text 0800 804 7463 SMS 07872 604 642

#### Meniere's Society

The Ménière's Society
The Rookery
Surrey Hills Business Park
Wotton Dorking

Wotton, Dorking Surrey RH5 6QT

Tel Helpline 0845 120 2975 Text 01306 876 883 Fax 01306 876 057

Email info@menieres.org.uk
Web www.menieres.org.uk

## Royal National Institute for Deaf People (RNID)

#### **RNID Scotland**

Empire House 131 West Nile Street Glasgow G1 2RX

Tel 0141 341 5330 Text 0141 342 5347 Fax 0141 354 0176

Email rnidscotland@rnid.org.uk

Web www.rnid.org.uk

#### **RNID Solutions**

Tel 01733 361 161 Text 01733 238 020 Fax 01733 361 199

Email solutions@rnid.org.uk
Web www.rnid.org.uk

#### Scottish Council on Deafness (SCoD)

Central Chambers

Suite 62

93 Hope Street Glasgow G2 6LD

Tel 0141 248 2474

Text 0141 248 2477 and 1854

Fax 0141 248 2479
Email admin@scod.org.uk
Web www.scod.org.uk

#### Sense Scotland

43 Middlesex Street

Kinning Park

Glasgow G41 IEE

Tel 0141 429 0294 Text 0141 418 7170 Fax 0141 429 0295

Email info@sensescotland.org.uk Web www.sensescotland.org.uk

#### Student Awards Agency for Scotland

Gyleview House 3 Redheughs Rigg Edinburgh EH12 9HH

Fax 0131 244 5887 Tel 0845 111 0244

Disabled student enquiries

Web www.student-support-saas.gov.uk

#### Text Relay (Telephone relay service)

PO Box 284

Liverpool L69 3UZ

 (voice)
 18002

 (text)
 18001

 (emergency)
 18000

#### **Customer Support**

Tel 0800 500 888 Text 0800 500 888

Email helpline@textrelay.org
Web www.textrelay.org

## Notes





#### Deaf Action Registered Office