



DeMENTia & DEAFness

What YOU need to know

Kate Allan
Frankie McLean
Liz Scott Gibson



Acknowledgements

We are grateful to the Queensberry House Trust for funding the development of a training session and the production of this booklet.

We would also like to acknowledge the Queensberry House Trust and the Scottish Executive for funding an earlier phase of work in which Deaf Action worked with the Dementia Services Development Centre, University of Stirling to produce *Dementia and Deafness: An Exploratory Study*, which is important background reading to this booklet. This document has been published as a PDF on www.dementia.stir.ac.uk and www.deafaction.org

Our thanks also go to Will Clark, Caroline Ewing, Lilian Lawson, John Killick, Mary Marshall, Drena O'Malley, Kate Stoker and Catherine Thompson for their help in writing this booklet.



Contents

About dementia	2	Working with hearing aid users	15
About deafness	5	About hearing aids generally	15
Acquired hearing loss	5	Day to day use – the basics	16
Profound or cultural deafness	6	Batteries	16
Deafblindness	6	Cleaning hearing aids	16
Physical disability	7	Helping people with dementia to use hearing aids	17
Learning disabilities & deafness	7	Supporting sign language users	18
Tinnitus	7	British Sign Language	18
Measuring hearing	8	Using BSL	18
What YOU can do to help	9	Writing things down	19
Is hearing loss a problem?	9	Fingerspelling	20
Vision is important too	10	Lipreading	20
Improving communication	10	Human aids to communication	20
Helpful ways of speaking	10	Working with interpreters	21
Nonverbal communication	12	Deafblind people and people with learning disabilities	22
The physical environment	12	Equipment which can help	24
Activities and routines	13	Where to find out more	Inside back cover & back cover



About dementia

*I'm forgetting things all the time...
oh dear! **

(Deaf service user)

The word 'dementia' is used as a general term for a number of related conditions. This includes the more common types such as Alzheimer's Disease and vascular dementia. The less common types include dementia with Lewy bodies and Pick's Disease.

About one in 20 people over the age of 65 has dementia. It can also develop in younger people, but it is rarer. More people will be diagnosed in the coming years as the UK population grows older. Most people with dementia live in their own home.

We do not know what causes dementia. For some people there may be a genetic aspect. There are now drugs which can help to slow down the rate at which things change. However, they do not 'cure' the condition.

** All the quotations come from 'Dementia & Deafness: An Exploratory Study' – details of how to get this report are provided in Acknowledgements.*

The main symptoms of dementia are:

- memory loss
- confusion
- difficulty with thinking and decision-making
- decline in skills needed for everyday living
- changes in ways of communicating

At first the individual's problems are likely to be fairly mild. They may get the details of recent events mixed up and have problems finding the right word or sign (if they are a sign language user). As the condition progresses, however, things become more difficult. Eventually they may stop using language altogether. Memory problems may progress until the person seems to be in a permanent state of confusion.

Although the symptoms of dementia usually involve losses of various kinds, it is very important to remember that the person who has dementia does not get 'lost'. They are still there, trying to understand things, trying to keep in touch with other people and do things which are important to them. They still have feelings, likes and dislikes and hopes for the future.

About dementia

Every person who has dementia experiences it in their own individual way. How the condition develops depends on the person's personality, history and personal circumstances. How those around the person behave towards them makes a big difference too.

Communication is a central issue. Often the person's ways of communicating will change over time. They may have problems finding the right words or signs and this might cause frustration. But they still need to remain in communication with those around them. So, we need to adapt our ways of communicating to suit the individual.

Trying to keep in touch with the person tells them that you know they are a unique and valuable person, and that their feelings and needs matter.

There are many ways to communicate. As well as words, there is eye contact, touch, and facial expressions etc. Sometimes simply offering a friendly smile and a reassuring touch will be more helpful to the person than using a lot of words. We should never say that a person

"can't communicate". Rather we should ask "How is this person telling me about their needs?"

It is important to help the person to remain involved in things which they enjoy and are familiar. They also need to keep as much control as possible over what is happening to them. This may lessen feelings of fear and anger, which can lead to the person doing things which other people find difficult (for example, hitting out or trying to get away from situations).

I think his hearing is a contributory factor in the sense that it affects their confidence because if they don't hear somebody speaking to them, and they've got this confusion with memory, it plays havoc with their communication.

(Relative of service user with acquired hearing loss)

Many people with dementia also have depression, although often it is not recognised or treated. The person may withdraw from activities and relationships, and generally lose their confidence. It is easy for others then to think these changes are caused by dementia, rather than realising that the person is depressed as well.

In common with other older people, many people with dementia also have hearing loss. Some of them will have been deaf from an early age. The difficulties which are part of dementia are made much worse when the person cannot hear properly. Our response to this situation will have a huge effect on how they feel and what they are able to do.



About deafness

*It's a horrible feeling - standing talking to somebody and they're talking back at you and you can't hear what they're saying...
You feel so stupid.*

(Service user with acquired hearing loss)

There are an estimated 9 million deaf and hard of hearing people in the UK; this means approximately 1 in 7 people.^{+ †} This number is rising as more people live well into old age. Most of them gradually lose their hearing as they get older – only 2% of young adults are deaf or hard of hearing. The proportion of deaf people starts to increase significantly around the age of 50; and 71% of the over 70 population are deaf or have significant hearing loss.[†]

Types of deafness

There are two main types of deafness: acquired hearing loss and profound or 'cultural' deafness. There are also people who have multiple sensory needs, such as those who are both deaf and blind, and those with physical and learning disabilities.

Acquired hearing loss

Deafness which develops during a person's lifetime is usually called 'acquired hearing loss'. There are two types of acquired hearing loss:

- **conductive deafness** – sound has difficulty in passing through the outer or middle ear
- **sensorineural deafness** – the cause of deafness lies in the cochlea or hearing nerve

Acquired hearing loss can come about through a variety of causes. Certain types of illness and injuries can cause deafness, which is either temporary or permanent. This can happen at any age.

Exposure to loud noise is one of the most common risks to otherwise normal hearing. Permanent damage to the ears can be caused by as little as one minute's exposure to loud music in a night club, for example!

^{+ †} See these symbols in 'Where to find out more' for source of information.

Profound or 'cultural' deafness

Hearing people should wake up about deaf people.

(Deaf service user)

People who are born deaf or have become deaf very early in life are often known as being profoundly or culturally deaf. Most deaf children (95%) are born to two hearing parents who will probably know nothing about Deaf people or sign language.

Many deaf people consider themselves part of the Deaf community (deaf with a capital D) and are comfortable with their own Deaf identity. Such Deaf people emphasise the importance of vision in their lives, and do not place particular focus on not being able to hear or speak particularly well. Some do not benefit at all from hearing aids and choose not to wear them. In the UK Deaf people use British Sign Language (BSL) as their first language. More information about BSL and ways of communicating with sign language users is provided later in this booklet.

Some will have attended Deaf schools, and it is common for Deaf people to marry other Deaf people. If they choose to do so, Deaf people can enjoy a fully participative social life within the Deaf community. There are clubs for Deaf young people and for older people, churches where BSL is used, Deaf drama and other arts organisations, and a wide range of sports clubs which participate nationally and internationally in everything from chess to football.

However, it is also true that Deaf people have much higher rates of mental health problems than the general population. This is probably related to the fact that people in the hearing world generally do not recognise the needs and abilities of Deaf people, and there is still a great deal of discrimination. You can find out more about the Deaf community by watching TV programmes such as 'See Hear' on the BBC.

Deafblindness

It is thought that there are 24,000 deafblind people in the UK. A much larger number have significant difficulties with both vision and hearing which are not classified as deafblindness.*

* See this symbol in 'Where to find out more' for source of information.

Deafblind people may have particular difficulties taking in information. Some may be likely to focus on a particular piece of information and get it out of context. This may make an individual appear to be confused generally.

Because of these factors they are at high risk of being 'informally diagnosed' as having dementia. If the person has some degree of vision and hearing, don't assume that this will lessen confusion. It may even make matters worse.

Physical disability

In common with many older people, Deaf people and those with an acquired hearing loss are likely to develop various sorts of physical disabilities as they grow older. Arthritis, in particular, may interfere with the ability of a sign language user to communicate, and general frailty or mobility problems will make communicating whilst moving around more difficult.

Learning disabilities & deafness

People with learning disabilities are more likely to be deaf or hard of hearing than those in the

general population. Many significant people with a learning disability also have a hearing loss. People with Down's Syndrome are also much more likely to develop dementia.

Well, I forget things... But I don't want to be in home with hearing people... Being with hearing people is lonely, lonely, lonely.

(Deaf service user)

Tinnitus

Tinnitus is the name given to a condition where a person hears sound which is not coming from outside the ears. This sound may resemble ringing, buzzing or whistling. In some cases it can sound like music or voices. The sounds may be present all the time or they may stop and start.

We do not know what causes tinnitus. It is estimated to occur in about 10% of the population (people of all ages), and about 5% are thought to have severe or persistent problems.♦ Tinnitus cannot be diagnosed unless

♦See this symbol in 'Where to find out more' for source of information.

the person experiencing it reports their problem. This means that people who have dementia may also be experiencing tinnitus without others knowing.

Some psychological treatments for tinnitus are available. These generally involve helping the individual to cope with their symptoms by diverting their attention away from the distressing sounds. Many people with dementia would find such methods difficult to learn. It has been suggested that avoiding stress, caffeine and loud noise are also helpful.

Measuring hearing

A hearing test, carried out in an NHS clinic or by a private company, identifies the quietest sounds a person can hear across a range of pitches of sounds (their thresholds). The higher these are, the greater the hearing loss.

0-19	Little or no difficulty following speech
20-40	Mild deafness; some difficulty following speech, especially in noisy environments
41-70	Moderate deafness; difficulty in following speech without a hearing aid.
71-95	Severe deafness; people usually rely on lipreading even with a hearing aid. BSL might be a preferred language.
95 >	Profound deafness; for those deaf from birth, BSL may be a preferred language.

Deaf and hard of hearing people choose to communicate in different ways depending on their level of deafness and/or preferences. For example, people with mild hearing loss may find that lipreading or using a hearing aid is most effective. People with more severe hearing loss might prefer to use British Sign Language (BSL), a speech-to-text transcription system, or rely on intensive lipreading. Deafblind people may use the Deafblind manual alphabet, or 'hands-on' signing.



What YOU can do to help

*Some people don't bother, you see
They don't understand how I'm
feeling.*

**(Service user with acquired
hearing loss)**

The following are some important things to remember – whether you are working with a person with dementia who has always been deaf or one who has become hard of hearing in later life:

- We **must** try to keep communication channels open.
- It is **not** acceptable to write the person off and assume that they are unable to understand you and have nothing important to tell you.
- Everyone is different - we need to adopt an individual approach.
- Sometimes we will not be sure if we have been successful or not – but we still mustn't give up.
- Keeping an open mind is essential.

Is hearing loss is a problem?

When you meet someone with dementia who seems unresponsive, don't just assume that this is due to their poor memory. Ask yourself what role hearing loss might be playing in the situation. If the person is over 70 it is likely that they will have some degree of hearing loss. Many will have a significant hearing loss.

*It takes time. If you're alerted to it
very quickly that's fine, but
otherwise it could be weeks down
the line and you realise someone's
having difficulties with
communication.*

(Care practitioner)

There are some simple things you can do to try to find out about how good a person's hearing is:

- Start by facing the person and talking normally.
- Avoid asking yes/no questions which mean that the person is more able to guess an appropriate answer. Open questions like "What did you have for lunch?" are more likely to reveal a problem with hearing.

- Then try casually covering your mouth as you speak. This will interfere with lipreading.

If you suspect that there is a problem which has not been picked up previously, the person should see their GP. Sometimes a simple intervention such as ear syringing may help. For others a referral to an audiology service or other specialist will be necessary.

Vision is important too!

Deaf people rely more on visual clues in day to day life, so making sure that the person is wearing clean, up-to-date spectacles is essential

And he complains about his eyesight as well. I know that he did have the start of a cataract, but he says that he cannot read a newspaper now. But with the communication being poor, how does he tell his optician about how he's feeling, how he sees?

(Relative of person with acquired hearing loss)

Improving communication

When someone has dementia so many things come down to language and communication.

(BSL/English Interpreter)

Helpful ways of speaking

- Choose a quiet place or minimise background noise
- Get the person's attention before you start speaking
- Make sure the person can see your face clearly and that it is well-lit
- Get onto the same level so they are not having to look up or down
- **Do not shout or raise your voice!** This will distort your speech making it more difficult to understand. It may also make you sound angry or impatient, and can be painful to the deaf person.
- Say clearly what the conversation is about.
- Keep the message simple

What YOU can do to help

- Speak a **little** more slowly than usual, but keep the natural rhythms of your speech. This will help the person with lipreading.
- Do not over-exaggerate your words as you speak.
- If the person is having difficulty understanding, try using different words to express your meaning.
- If the person is comfortable with reading, you can also try writing down your message.

Every voice and situation is different. So there will be times when an individual can hear more clearly than others. But it is NOT fair to say things like “He can hear when he wants to”! Also, when communicating with someone who is hard of hearing, never give up and say “It doesn’t matter” or “Never mind”. Deaf people often find this upsetting.

(About people speaking very loudly):

Oh, not good at all. No... you don't want that because it can sometimes be disconcerting that – a louder voice.

(Service user with acquired hearing loss)

Bear in mind that if the person has been hard of hearing for some time, they will probably have developed some lipreading skills (although they may not be aware of it).

Nonverbal communication

I have to work in conjunction with my eyes. You have to think of things, to associate what you see and what you hear... Gestures... It's important for people like myself who are hard of hearing to associate fairly quickly with what they're saying. ... I need visual as well as hearing aids.

(Service user with acquired hearing loss)

The following points are some ideas for making the most of nonverbal communication:

- Try to be relaxed and friendly – smile!
Avoid any signals which might make you seem impatient.
- Make sure that the person can see your face clearly – don't sit or stand with your back to the window or other source of light.
- Do not cover your mouth with your hand or anything else while you speak.
- Use eye contact to hold the person's attention.

- Use gestures to back up what you mean, but avoid moving your hands around too much as this can be distracting.
- Use your fingers to give important details like numbers.
- Get close enough to the person to have a conversation, but not so close they feel crowded.
- If it seems appropriate, touch can also be useful.
- Use objects or pictures to help the person to understand what you are telling or asking them.

The physical environment

Take some time to think about how the physical surroundings might be affecting the deaf or hard of hearing person:

- Reduce background noise wherever possible. TVs, radios etc should be switched off when no one is paying attention to them.
- Think about whether there are other sources of sound which could be distressing, for example fans/extractors, alarms, telephones etc
- Try to ensure that there are soft furnishings

What YOU can do to help

in rooms. They absorb sound and stop it echoing around.

- For rooms with hard floors, minimise noise created by chairs etc moving by fitting rubber ends on chair legs etc.
- Do not position yourself with your back to a window or other source of light. Your face will be in shadow and difficult for the person to see.
- Bear in mind that for a deaf person being in the dark may cause significant anxiety as they will be cut off from any kind of communication.

What about when there are 3 or 4 people all speaking in a group?

A rabble!

What does it sound like to you?

Just everybody talking at once!

(Conversation between researcher and service user with acquired hearing loss)

Activities and routines

You're out of company – you're just left to get along yourself. ... Maybe I'm a wee bit sad about that. ... to get so-and-so "Oh he can't hear you" – just like that.

(Service user with acquired hearing loss)

How much do the routines and activities in your service include people with dementia who are deaf or hard of hearing? These questions should start you thinking...

- When people come together for social activities (for example quizzes, bingo etc) how easy is it for those with poor hearing to participate?
- How many people come together at once to take part in activities?

What about mealtime arrangements?

- How noisy is the place where people eat?
- Are chairs and tables moved on hard floors? Is there a radio on in the kitchen?

- What opportunities do deaf or hard of hearing people have for making choices?
- Are the ways in which people sit around the room or around tables helpful?

The things you can do to help will depend a lot on the kind of service you work in. But bear in mind the following points:

- Think about providing opportunities for fewer people to meet on any one occasion.
- For group activities, think about who needs to sit nearest to the focus of the activity.
- Keeping noise levels down as much as possible makes things easier for everyone.

I have missed out on a lot. I've wanted to go to clubs and things, and I know that I'm going to be a nuisance to people because they're having to repeat themselves to you.

(Service user with acquired hearing loss)

- Providing visual information to back up spoken information is helpful. Think about using both words and pictures.
- Show people things, for example meals, rather than relying solely on descriptions and spoken questions.
- Make sure lighting levels are adequate to help people to use visual information.
- Give thought to where people sit and who is near who. Minimising the likelihood of tension or arguments is important.
- Find out directly from people what sorts of things they enjoy and how best you can help them to remain involved.



Working with hearing aid users

About hearing aids generally

I can't do without my hearing aid. I'm lost without it. ... I would say it is a marvellous thing. Aye, it's not something you can do without once you start with it.

(Service user with acquired hearing loss)

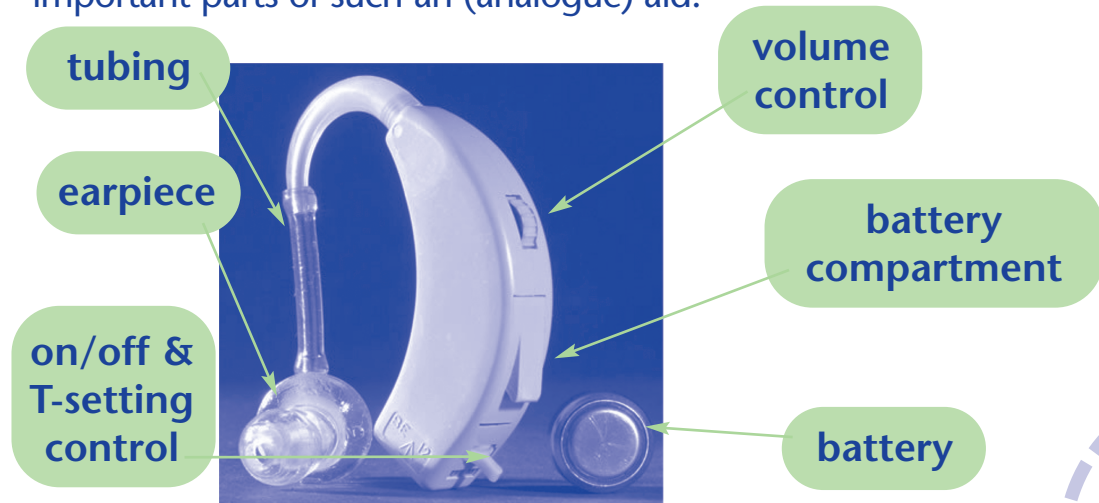
Hearing aids work by increasing the strength of sounds that the person hears. Some increase all sound (analogue types), others are more selective (digital types). They can offer a real improvement in communication and other activities, but they also have some disadvantages:

- They are not suitable for all deaf people.
- Background noise can be amplified making it difficult to concentrate on meaningful sound.
- They can be physically uncomfortable.
- They make unwanted sounds if not fitted correctly.
- They need constant maintenance.

Although hearing aids can help people a great deal, they do not return an individual's hearing to normal. Don't assume that as soon as someone has their hearing aid in they can hear perfectly. Even if it is working well, they will need time to adjust to the way things sound.

It takes time for a new hearing aid user to become accustomed to the aid. A person with dementia will take even longer and need extra support.

There are several different types of hearing aid. The most common is a behind-the-ear hearing aid. This is worn with a piece in the ear and part of it at the back. This diagram shows the important parts of such an (analogue) aid:



Analogue hearing aids have a 'T setting' (telecoil) which works in a different way from usual. The user has to put their aid to the T setting when technology (an induction loop) is available, for example in a large room, public places etc. Induction loops create a magnetic field inside a loop which works with the hearing aid.

An inside-the-ear hearing aid has all the technology in the one part (as shown in picture).

It is also now possible to get much smaller aids which fit inside the canal of the ear.

NHS Audiology Departments (which assess hearing and prescribe hearing aids) often have long waiting lists as demand for their services is very high. As well as NHS clinics, there is a range of private providers of hearing aids.

Day to day use – the basics

A hearing aid has to be switched on for it to work! Forgetting this is a common mistake. Switching it off at night is important for conserving batteries.

The volume of analogue aids needs to be set by the user or their carer. If it is too high, it will whistle. If it is too low it will not be effective. Note that whistling may also be caused by a badly fitting earmould or the mould not having been inserted correctly.

Batteries

Hearing aids rely on batteries which have to be checked and changed. Batteries should be replaced before they run out. Depending on the type of hearing aid, batteries may last only a few days to about 3 weeks. New batteries are available free from your local Audiology Department

Cleaning hearing aids

Hearing aids must be cleaned regularly or they will become blocked with ear wax and other dirt. Behind-the-ear aids should be cleaned by detaching the mould and tube from the part which contains the technology. **It is vital not to get this part wet!** The mould and tube should be washed in warm, soapy water (do not use detergent). Wax can be removed with a soft brush. The tube needs to be completely dry before the aid is used again – water droplets will distort the sound.



If detaching and washing the mould and tube is too difficult, it can be cleaned (daily) with an antiseptic wipe and by using a small hook or brush to remove wax.

Inside-the-ear hearing aids can **only** be cleaned using antiseptic wipes. They must **never** get wet.

The tubes on behind-the-ear hearing aids must be changed approximately every 6 months or they will become rigid and fail to work properly. Spare tubes are available from Audiology Departments.

...she sleeps much more when the hearing aids are either not in or not on. But it's amazing what a difference it can make once they're switched on and she goes out ... this man spoke to her and her, from going like that (indicates head down), her face just lit up and smiled.

(Relative of service user with acquired hearing loss)

Helping people with dementia to use hearing aids

Some people with dementia will have started to use their hearing aid before the onset of their memory problems. Such individuals are likely to be more confident with their aid, but may still require support and encouragement to use it.

Helping someone with dementia who is new to a hearing aid to start using it is more complex. The following ideas may help:

- Don't expect the person to get used to it quickly – it is likely to take a lot of time.
- Encourage the person to try using it for very short periods initially, and then gradually extend them.
- Encourage the person to begin using their aid in fairly quiet, calm circumstances.
- Bear in mind that things will sound very different to the person at first – this may cause distress or disorientation – reassurance will be necessary.
- For some people providing simple written or pictorial information about the aid for the person to refer to may be helpful.



Supporting sign language users

British Sign Language (BSL)

*I go to a day centre. I draw...
I'm always drawing. It's ok ...
but hearing. No signing. I sometimes
don't know what's going on. I say
'Hello' sometimes but... I want a
day centre where people can sign
and I know what is going on.*

(Deaf service user)

It is estimated that 50,000-70,000 people in the UK are BSL users. It is primarily used by those who are deaf from an early age, but lose their hearing later in life who use it as their language of choice.

BSL is a language in its own right which has evolved over hundreds of years. It is a visual-spatial language, with its own grammar, structure and principles. Its word order is quite different from that of spoken English. It calls upon many features in order to express meaning, including hand shapes and movement; facial expressions; body language and the use of space. Some people use Sign

Supported English (SSE). This is not a language in its own right, but is a form of English accompanied by signs. BSL has recently been officially recognised as one of the indigenous minority languages of the UK.

Using BSL

Even having a knowledge of Deaf culture, and the role and limitations of an interpreter would be better. They wouldn't necessarily need to know the language itself.

(BSL / English Interpreter)

Although learning to use BSL fluently requires attending classes, it is possible to learn a few signs which would allow you to communicate about basic things. (See back cover for sources of information.)

However, if you are not a fluent BSL user and need to communicate detailed information, then it is better to use a BSL/English interpreter. Information about this is provided later.

When sign language users develop dementia, some changes in their use of BSL seem to occur:

- Some revert to using signs learned at an early stage in their life.
- Some may find it difficult to recall the sign they wish to use.
- Use of signing space (clearly defined in BSL grammar) seems to shrink.
- The range of handshapes used tends to reduce (the fine movements required to produce some handshapes appear restricted).
- The production of signs seems less exact.
- The signs used to show whether things happened in the past, are happening now, or will happen in the future are less clear, with the potential to cause even more confusion.

When using BSL with a Deaf person with dementia, try to:

- Use a more simplified sentence structure.
- Repeat what you have understood in BSL to clarify the issue.
- Make sure the Deaf person watching you

has time to track the movement of your signs with their eyes.

- Be more specific when locating things in space; it is not always helpful to point.

Writing things down

Deaf sign language users tend to have less developed skills in reading and writing English. Remember that for Deaf sign language users English (or any other spoken language) will be a second language, and they may not be confident with spelling. Writing things down can be helpful to some people, but do not assume that it will suit everyone. Not every Deaf sign language user will be familiar with written language.

Also, for people with dementia the ability to understand writing may deteriorate. Having relevant objects or pictures to hand may help considerably.

Fingerspelling

I worked with someone in hospital and one nurse could fingerspell a bit, she's been on an awareness training course, and when she was around he [the service user] was quite bright but he faded when she wasn't on duty.

(BSL/English Interpreter)

Fingerspelling is used as a part of BSL, usually for the names of people or places, or an unfamiliar item. It is a system of communication where each letter of a word is spelt out using the fingers and hands. The two-handed version is used throughout the UK, and can be slightly adapted to be used by deafblind people. Deafblind people may also use another system known as 'block' which involves tracing out letters on the palm of the deafblind person's hand.

Remember that fingerspelling is a form of English, which not all BSL users are comfortable

with. Also, if someone has dementia, they may find fingerspelling even more difficult. You may need to go quite slowly.

Lipreading

Many Deaf sign language users (and people with acquired hearing loss) have developed the ability to lipread people who use spoken English. However, this ability may diminish if a Deaf person develops dementia, and they are likely to find lipreading quite demanding. Remember spoken English is usually not their first language. You need to take this into account when trying to communicate. Don't try to do too much at once. Although it is a valuable means of communication, there is still a lot of guesswork involved in lipreading.

Human Aids to Communication (HACs)

It may be a good idea to think about bringing in someone who is specially trained to facilitate communication between hearing and Deaf people.

Human Aids to Communication (HACs) may include:

- **BSL/English interpreters** who will interpret from one language to the other. This could be from spoken/written English to BSL, or vice versa.
- **Lipspeakers** who clearly repeat what someone has said without using their voice, so that the Deaf or hard of hearing person can lipread them.
- **Speech-to-text** reporters type every word that is said using a special keyboard. The words appear on a computer screen.
- **Notetakers** write or type a summary of what has been said onto paper or into a computer.
- **Deafblind communicators** help hearing and deafblind people communicate with each other.

Working with interpreters

BSL interpreters are the most important resource in communicating with Deaf sign language users. They can be booked by contacting Deaf Action or other organisations (such as SASLI - see back cover for contact information.)

When using an interpreter, try to provide information about the discussion which is going to take place beforehand. This will allow the interpreter to prepare properly.

Thought needs to be given to the seating arrangements. Interpreters should sit opposite the Deaf person in order to give clear visual access. When the conversation is going on, speak directly to the Deaf person (don't say "Tell her..." etc) , and look at them while you are talking to them and they are signing back.

Only one person should speak at any one time. There will be a slight delay whilst the interpreter translates your words into sign language and for the Deaf person to respond.

If the person's signing seems very confused, it might help for another Deaf person to act as an intermediary between the interpreter and the person with dementia.

Interpreters need breaks. Allow 10 minutes for every 40 minutes of interpreting work. Remember that there are other sorts of 'human aids to communication' (detailed above). Find out which is the most useful for a particular individual.

Communicating with deafblind people and people with learning disabilities

Much of the advice detailed earlier in this booklet also applies to communicating with someone who is deafblind. Again, as stated earlier, it is vital to support a person with deteriorating vision as much as possible by having regular eye examinations, and having them wear up-to-date spectacles which are clean.

A simple way of communicating with some deafblind people (usually those who have been deafblind for a long time) is the 'block alphabet'. This involves tracing the shape of letters (in capitals) on the palm of the person's hand. Other deafblind people use a 'manual alphabet' which is related to the fingerspelling alphabet used by Deaf people. This is quick to learn. Sign language users who may be gradually losing their sight (this is known as 'Usher Syndrome') may still understand sign language if it is adapted to suit their restricted vision and those who lose their sight later in life may use a form of 'hands on' sign language. However, for a deafblind person who has dementia, bear in mind that there are likely to

be changes in the ability to use such skills. Remember to allow the person extra time.

For further information about deafblindness, see 'Where to find out more' at the end of this booklet.

It was so sad when he went on a visit to the new place (a signing environment), they signed to ask him if he wanted a drink and he replied he wanted a coffee. The worker from the nursing home was with him and said 'but he always has tea' and he did. Since he has moved and can sign to the staff about what he wants he nearly always has coffee, it's rarely he has tea now. All those years when they just brought him tea!

(Relative of Deaf service user)

Supporting sign language users

Some people with a learning disability who are also deaf may have learned to use a communication system such as Makaton or Signalong. Being able to communicate well will require that you learn the signs which are most important in day to day life.

Remember that pain, discomfort or tiredness will interfere with an individual's ability to concentrate on conversations. Try to find the best time of day, ensure that the person is not in unnecessary pain or discomfort, and keep interactions short so that they do not become exhausted.



Equipment which can help

We have flashing lights and doorbells to help us... we're just like everybody else.

(Deaf service user)

In addition to hearing aids, Deaf and hard of hearing people can use a range of other types of equipment which can help them do everyday things.

People who have longstanding deafness often use specialised telephones which allow them to communicate with others by typing messages. These are called 'textphones'.

A service exists which allows a hearing person to communicate with a Deaf person by talking to a 'go-between' who then types the message.

Texting on mobile phones has become a popular way for Deaf people to communicate with each other and hearing people.

There are a variety of devices available which tell a person who is Deaf or hard of hearing that, for example, there is someone at the door

or an alarm clock has gone off. These devices may use flashing lights or vibrating pads. Equipment exists to help hard of hearing people to hear the television without it having to be turned up very loudly. Some devices connect with a person's hearing aid (through the T setting on a loop system). There is an alternative for people who do not use hearing aids. This involves the person wearing a set of headphones which pick up a transmitter from the television.

Deaf people who develop dementia may need help in continuing to use equipment which they may have relied on for a long time.

Do not assume that a person with dementia who has become hard of hearing will automatically be unable to use equipment of this kind. They may need extra support and encouragement, but it could make a huge difference to their quality of life and that of others.

If you would like to find out more about what sorts of equipment is available and how to access it, look up "Where to find out more" at the back of this booklet.



Where to find out more

Books

Mansfield J (2004) *Effective Communication with People who have hearing difficulties*
London: Speechmark *

Miles D (1988) *British Sign Language: A Beginner's Guide*.
London: BBC Books.

Smith C (1992) *Sign in Sight: A Step into the Deaf world*.
London: Souvenir Press.

Lysons K (1996) *Understanding Hearing Loss*:
London: Jessica Kingsley Publishers.

Organisations

Deaf Action can provide advice and information about deafness and specialist equipment. They also run BSL and Deaf Awareness courses and provide training for organisations.

Deaf Action (Head Office)+
49 Albany Street
Edinburgh EH1 3QY

Tel (voice): 0131 556 3128

Tel (text): 0131 557 0419

Fax: 0131 557 8283

Sms: 07775 620 757

Videophone: 82.71.100.121

E-mail: admin@deafaction.org

Web: www.deafaction.org

**To find out more about dementia
(for practitioners), contact:**

Dementia Services Development Centre
University of Stirling
Stirling FK9 4LA
Tel: 01786 467740
Fax: 01786 466846
Email: dement1@stir.ac.uk
Web: www.dementia.stir.ac.uk

(for family members)

Alzheimer Scotland
22 Drumsheugh Gardens
Edinburgh EH3 7RN
Tel: 0131 243 1453
Fax: 0131 243 1450
Web: www.alzscot.org

The following organisations also have useful information:

Council for the Advancement of
Communication with Deaf People
www.cacdp.org.uk

Deafblind Scotland
www.deafblindscotland.org.uk

Deafsign
www.deafsign.com

Hearing Concern
www.hearingconcern.com

Royal National Institute for Deaf People
www.rnid.org.uk ♦

Scottish Association of Sign
Language Interpreters
www.sasli.org.uk

Scottish Council on Deafness
www.scod.org.uk

Sign Community: British Deaf Association
www.britishdeafassociation.org.uk