



COMMUNICATION AND NF2

Much of the information in this Fact Sheet has been taken from a talk given by a mother of a young person who has NF2.

NF2 brings with it a number of difficulties that make communication a challenge. It is only when problems arise that something we have taken for granted becomes significant. Time and energy put into finding alternative ways to communicate is never wasted. Acknowledging that you might become deaf and might need help is very difficult before it occurs; getting that help at an early stage whilst hearing is still present is usually helpful.

What is communication?

- Communication is about sharing what matters to us.
- The ability to receive another person's thoughts.
- The ability to respond to others.
- The ability to let another person know your needs, likes and dislikes.
- The ability to share your emotions with others.
- The assurance that you are of value and have an important and useful part to play within your social circle – and maybe beyond!

How do we communicate?

- Through our senses: sight, smell, touch, hearing.
- Through words: written or spoken.
- Through body language.

Why do we communicate?

- To share our thoughts.
- To build up relationships.
- To express our needs.
- To achieve specific aims.
- Because it's human!

How does NF2 affect communication?

- Hearing loss.
- Facial nerve damage may lead to speech difficulties, disfigurement and loss of confidence.
- Balance difficulties with restriction of social activities and loss of confidence.
- Tiredness and lower concentration levels.

How can you overcome these difficulties?

Hearing loss

Hearing loss in NF2 can be gradual or sudden and each brings its own difficulties. Adjustment to this loss is never easy and takes time. Friends and family are there to help with this big change in your and their lives. Professionals can supply the information and support to make the change more manageable.

Learning to lipread is important. For some learning sign language opens up new opportunities.

Facial nerve damage

Ask a close friend or family member to assess how difficult it is to understand you – you may be very surprised to find it's not as bad as you fear. Try to look positively at people when you meet them as this makes it easier for them to respond to you and see beyond the facial nerve damage. Try to remember that even the most beautiful models usually have some part of their body they don't like – we're all the same under the skin! Don't try to cover the facial nerve damage with your hand or hair as this only distances you further from people and makes it harder to communicate.

Balance difficulties

Explain to people (if necessary) about the balance difficulty so that you feel safe and confident. Take a friend along with you for support as well as helping you to have a good time! You may prefer to use a walking stick which also alerts others to your needs without you needing to spell it out. If possible, check out new venues before visiting eg steps, parking, lighting, noise levels.

Tiredness

Recognise and accept your limitations. Plan ahead for important events. Explain to others so that they understand the issue. Make sure you get enough rest. Don't be unduly hard on yourself when you think you should be able to do more!

Ways to keep communication lines open

| | |
|---------------------|-----------------------------|
| Love | Realism |
| Patience | Openness |
| Understanding | Optimism |
| Determination | Accessing professional help |
| Humour | Asking questions |
| Inventiveness | Sign language |
| Lip-reading classes | |

The majority of people are only too happy to communicate, but sometimes they feel embarrassed – not sure of the best way to do so. If you explain your needs, with humour and clarity, most people are relieved to be given the tools that they need to chat to you, to enjoy spending time with you and to get to know you. It is important to recognise that people do not usually want to be unhelpful or unkind – they just need a bit of help to understand the situation. Generally speaking, it is better to ask someone to repeat themselves than to agree to goodness-knows-what!

As a precaution – always have pen and paper to hand.

Communication is essential to health and happiness and equal access to communication is a fundamental right for all.

How can you help yourself?

Finger spelling is quick and easy to learn. Its use is unobtrusive and is an invaluable backup to lipreading. If you get stuck on one word, being given the first few letters of that word gives you the clue you need.

Encourage your friends and family to teach themselves. Cards illustrating finger spelling are available from the RNID.

Lip reading Tuition

Lipreading does not just involve following the shapes of lips. The lipreader is also looking for other visual clues, including facial expressions, gestures, body language and clues from the situation you are in. Valuable clues can also be found from speech rhythm, stress, emotion in the voice, knowledge of the subject and anticipation.

Contact your ENT Specialist, the Hearing Therapist at your local Audiologist Department or your local council about adult education classes. The Association of Teachers of Lipreading to adults can supply details of your nearest Lipreading Class. www.lipreading.org.uk

Sign Language Tuition

Contact your ENT Specialist, Hearing Therapist or local Council to find your nearest class.

Communication Aids eg using the telephone, pagers, door bells and alarms

Contact your local Social Service Department to arrange a meeting with a Specialist Worker for people with a sensory impairment.

Adjustment to deafness

Contact the Hearing Concern Link in Eastbourne to find out about their week long courses which help people who are anticipating deafness or who are newly deafened.

Nerve Tumours UK have an Information Sheet about the service provided by Hearing Link. www.hearinglink.org/nf2programmes

Help with Speech difficulties

Talk to a Speech and Language Therapist at your local hospital.

To find a Sign Language Interpreter eg for a hospital appointment

Contact the hospital direct.

A **Lipspeaker** is a hearing person who is trained to repeat a speaker's message to lipreaders (the deafened person) without using the voice. A Lipspeaker may be employed to aid communication between lipreaders and hearing people in a range of situations, for example: adult education, conferences and meetings, job interviews, GP and hospital appointments. Names of Lipspeakers can be obtained from The Association of Lipspeakers.

www.lipspeaking.co.uk

The National Telephone Relay Service enables the deafened person to communicate by telephone with people who can hear and with people who are deaf, using a text phone.

Contact Typetalk on: 0151 709 9494 (voice and admin) or 0800 500 888 (textphone and helpline)

Learning to drive

The Queen Elizabeth Foundation Mobility Centre can provide a list of driving instructors around the country who are willing to offer lessons to people with a variety of health problems, including hearing impairment. They also have some written information.

For further information contact them at Damson Way, Fountain Drive, Carshalton, Surrey SM5 4NR or Email: info@mobility-qe.com www.qefd.org/mobilitycentre

Communication tips

Communicating with deafened people who lipread

- Stand or sit facing the person, three to six feet away, and at the same level as them.
- Face the light — do not position yourself in front of a bright window.
- Make sure people are not moving around behind you; do not stand in front of a wall with brightly patterned paper on it.
- Ensure that background noise is kept to a minimum.
- Check that the deafened person is looking before you start to speak.
- Do not shout as this will distort your voice and lip patterns — speak clearly with a normal rhythm of speech.
- Be brief. Stick to one point at a time.
- Remember sentences and phrases are easier to lipread than single words.
- If the person you are speaking to does not understand a word or phrase, rephrase what you have said.
- Give the deafened person you are talking to time to absorb what you have said.
- Keep your head still; stop talking if you turn away.
- Keep your hands and anything you are holding away from your face.
- Do not eat while you speak.
- Avoid exaggerated facial expressions and lip movements.
- Use gestures where these are relevant.
- If you are talking to deafened and hearing people, do not forget the deafened people.
- If you change the subject, make sure the deafened person knows. One word will give the clue to the next subject.
- Do not wear dark glasses. Much can be said by your eyes.
- Check that the deafened person is following what you say — lipreading is tiring.
- Write things down if you need to clarify them.
- Never say "It doesn't matter". It **does** matter or you would not have said it.

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Please seek further information from www.nervetumours.org.uk, or contact our helpline on the details above.

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