



Hearing Link's residential programme for NF2

Hearing Link is the national organisation that helps hearing impaired adults and their families to manage the impact that hearing loss can have on their lives. The organisation makes it easy for people to find information, support and ways to connect with others. It also brings people together so experiences can be shared and feedback can be gathered and passed on to service providers.

Hearing Link focuses on adults who have acquired hearing loss during their lifetime and who prefer to communicate through the spoken and written word rather than sign language. It delivers highly personalised services and specialises in helping people to adjust and manage the practical, emotional and social challenges that hearing loss can bring.

Hearing Link is the only organisation in the UK to offer a rehabilitative service that specifically addresses the needs of people with a diagnosis of Neurofibromatosis type 2.

What is the NF2 programme?

The programme is a week long residential rehabilitation service attended by up to 8 adults with hearing loss. Participants are also encouraged to bring along a family member, partner or close friend.

Known as Hearing Link's Intensive Rehabilitation Programme, the aim of the week is to help people adapt to hearing loss and to equip them with the skills and information to manage their changing health status. Through increased knowledge and understanding people with NF2 are helped to manage the emotional and practical challenges the diagnosis brings.

The Programme is based on peer education principles and there is a balance of tutors who have an acquired hearing loss, are affected by NF2 or have a professional interest in it's contents, for example specialist nurses, and therapists in hearing loss. It tackles many of the problems associated with NF2: communication difficulties, impaired balance, and tinnitus. The Programme also examines the resources available to support and assist people in adjusting to the challenges that hearing loss can bring.

The week is both formal and informal with plenty of opportunity for everyone to share experiences - the tutors actively encourage a participative approach. The Programme covers practical skills such as lip-reading, information about equipment, implants (cochlear and ABI) and employment issues, as well as communication, relaxation and the effect of this diagnosis on personal/family relationships.

Although Hearing Link runs many courses for people with hearing loss, the NF2 Programme is specific to this group of people and their particular health needs. There is also a focus on supporting the needs of carers and helping them understand the impact of acquired deafness, how best to help and to teach coping strategies.

Where do the courses take place?

Hearing Link is based in Eastbourne in East Sussex, and at least one NF2 week will be based there each year. However, Programmes are also set up in other parts of the country to help people avoid having to travel long distances to the venue. The same professional team will run the Programme wherever the location is.

What is the cost?

Anyone wishing to attend the Hearing Link NF2 Intensive Rehabilitation Programme will have their place funded through the NCG NF2 budget that supports the NF2 clinics. Almost all NF2 patients in the UK are now managed at one of the 4 major NF2 centres (or their satellites) and so anyone wishing to make an application can discuss things with their consultant.

The only cost to attend the Hearing Link NF2 Intensive Rehabilitation Programme is travel costs. Accommodation, food and the programme fee are all covered.

If you need additional financial support to enable you to attend the Programme then this can be discussed with the NF2 team: the nurse specialist or NF Specialist Advisor.

Where can I find out more information?

There is a website at www.hearinglink.org/nf2programmes which will give you more information and contact details for Hearing Link.

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What some people say about Hearing Link's Intensive Rehabilitation Programme:

... "it was a life changing experience for me... The chats I had with people really lit a fire within me and I noticed myself changing from the disaffected and miserable person I had become to my old self again".

... " I can't really explain to you how they did it ...or what happened ...but somehow I felt more positive and that NF2 was no longer the only thing about my life"...

... " it gave me back my confidence and I am going to go to lip-reading classes which I have kept putting off"

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Neurofibromatosis Specialist Advisor

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August 2012

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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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