

**Hearing Concern LINK** is the only national organisation in the UK providing specialist intensive rehabilitation to deafened adults. The service is delivered through a week-long residential programme, each attended by 5 to 7 deafened people, most of whom are accompanied by a family member or partner. The aim is to assist psychological adjustment to deafness. The week takes a holistic approach and the programme is tailored to meeting individual needs. It is grounded in peer education principles and has been developed by a multi-disciplinary team comprising doctors, qualified therapists in hearing, communication, balance, speech and language and psychology. It is delivered by these professionals and by tutors, some themselves have an acquired profound hearing loss.

The programmes aim to set everyone at ease in an informal atmosphere where deafened people are not disadvantaged. Communication support is such that no one is left out and the hearing partner is equally acknowledged; hearing loss is not simply the problem of the deafened person. Practical skills are learned, including lipreading, deaf awareness, and use of textphones and techniques for coping with balance problems. Individuals have the opportunity to discuss emotional difficulties they might be experiencing as a result of their deafness, as well as learning to be more assertive and increase confidence levels. Last, but by no means least, care is taken to ensure that where at all possible, local support is found for the deafened person upon their return home.

We aim to run at least one programme per year especially for people who have Nf2 and who are at any progression of the condition. Many come in the early stages of deafness with the knowledge that as the tumour develops the level of hearing will deteriorate. They are therefore able to equip themselves and their partner/family, with deaf awareness strategies and communication skills in preparation for the future.

Anyone wishing to attend a Hearing Concern LINK programme can in the first instance contact us at:

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A medical referral will ultimately need to be obtained but most people with a confirmed vestibular Schwannoma will be eligible for a place on a Hearing Concern LINK programme. Funding is normally provided from within the NHS.

## **MY WEEK AT HEARING CONCERN LINK, EASTBOURNE.**

I lost my hearing 15 months ago following an operation to remove an acoustic neuroma (vestibular Schwannoma) that was supposed to save my hearing. My fiancé of three years had broken up with me two days before my operation, so within the space of a week I lost my partner, the house I shared with him and my hearing. Three huge blows, including one that would affect me for the rest of my life.

To say the months that followed were a nightmare would be a huge understatement – I cried, I screamed, I refused to leave the house. I was taking anti-depressants and I could not even picture a future that contained any happiness in any way. I felt like a 'freak' and no one understood how I felt or could share my feelings, especially my family. I felt constantly panicked and continually stressed. What would I do when I bumped into old friends who did not know about my hearing loss? How could I explain to people that I am deaf when my long hair covers my aid? Can I communicate with people that I don't know? How can I cope with situations like the train station or airport? And horror of horrors, how do I go back to work and feel like a valued employee and not someone to be pitied or given menial tasks?

The Link Centre was recommended to me by my consultant and my mother and I went to their headquarters in Eastbourne for a residential week specifically for NF2 people at the end of May. It always sounds really naff and cheesy to say that a week changed your life but it really did, and I can express nothing but gratitude and admiration towards the people that run it.

Before I went to the Link Centre, I had never met another deaf person, let alone someone else with NF2, but there were 3 other people on the course that had NF2. I cannot describe how much of a relief and how reassuring it was to meet people who shared the same fears and difficulties as me. The Link Centre provided us with a safe and secure environment where people were willing to talk openly about their experiences and feelings.

Everyone on the course was affected to a different degree by NF2, but we had numerous breaks and appropriate communication support to ensure that everyone was happy and comfortable. The week was mostly supported by a palantypist, again something that I had never encountered before, although there were sessions led by people with sign language skills.

We had various people come into the hotel to give talks – people with NF2 that have gone on to live fulfilled and successful lives, individuals that had had implants and were sharing their experiences, specialists in balance, tinnitus and relaxing skills, and a demonstration of Sign Support English and Sign Language, to name but a few. There were also talks with the staff of the Link Centre regarding employment, personal goals, and future development.

For the hearing members of the group such as parents and siblings there was a counsellor to discuss their thoughts and feelings regarding a loved one losing their hearing and how to cope. It is very easy to forget that people who can hear have problems dealing with deafness too. The Centre also arranged for a visit to an deaf equipment centre which showcased up to the minute technology and gadgets for deafened people such a doorbells, vibrating alarm clocks and laptops that use voice recognition software for use in a meeting scenario at work.

The general feeling throughout the week was that the staff at the Link Centre could not do enough to help you. They thoughtfully provided notebooks and pens for communication between students, arranged flashing door lights for the hotel rooms, and even took everyone out bowling for the evening. All the staff were always present all day every day in case you had a problem, query or just wanted a chat.

I started the week with the Link Centre like a real life Kevin the Teenager – surly, aggressive, with the biggest chip on my shoulder, and a real ‘why me?’ attitude. I would love to say that I changed overnight, but that would not be true, however, I certainly left a much more patient, positive person with hope for the future. The three people on the course with me were an absolute inspiration and I cannot thank them, or the staff, enough for their efforts, time, patience and constant supply of alcohol!

Six months later and I am now a full time student at college studying for a diploma in Holistic Therapy. A week after coming back from the course I had the confidence and determination to chuck in my old job that I detested and to retrain in something new that I enjoyed. I also have a new boyfriend that I recently went on holiday with and I have set up my own Holistic Business.

**None of this I ever dreamed would be possible prior to going to Hearing Concern Link.**

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