



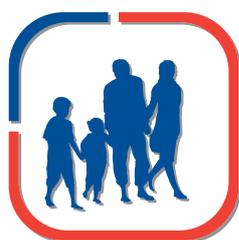
DeafHearie

Services for Deaf & Hard of Hearing People



Coping with Diagnosis

A Factsheet for Parents of Deaf and Hard of Hearing Children



Parents Corner



Coping With Diagnosis

This Factsheet provides information for families of children diagnosed with a hearing loss.

Coping with the Diagnosis

The majority of children who are identified with a hearing loss are born to hearing parents, so you may have very little knowledge or experience of hearing loss; there might not be a history of hearing loss in the family and you may not know any other families in the same situation. It is possible, that when you were actually given the diagnosis you might not have taken in properly what the professional said to you.



The time of diagnosis can be difficult for some parents and families. You may go through an array of emotions, which could include shock, denial, pain, guilt, disbelief, sadness, fear, anger, confusion, frustration, isolation, fear of coping, reflection, relief at getting a diagnosis, adjustment and acceptance. Also, at this time you may be confused by meeting all the professionals, the new terminology, or anxious about making the right decisions for your child with limited experience and knowledge.

These feelings are not unusual and it is an on-going process. Be prepared for good and bad days and it is important to remember it is ok to feel like this. On the other hand, you may not be feeling any of these emotions and you may have accepted the diagnosis without any major reaction. Be assured that there is no right or wrong way to react, and the way you are reacting is right and normal for you.

The age of diagnosis can also influence parents' feelings at this time. From 2011, the HSE plan to screen more children at birth for hearing loss, so in the near future more and more children will be diagnosed with hearing loss at a younger age. Newborn hearing screening programmes generally aim to reach a diagnosis of hearing loss as early as 3 months of age. As well as facilitating early intervention, this also gives parents more time to find out about deafness and their child's hearing loss.

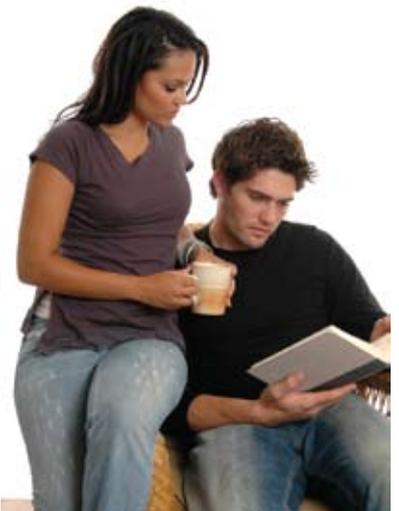
If diagnosis is late, parents can feel under pressure to make decisions quickly to try and 'catch up' and make up for lost time. Even if diagnosis is late, parents should be supported to take a little time to adjust and be assured that taking a couple of weeks to do this will not have an impact on their child's overall development.

DeafHear and its staff have a wealth of experience and knowledge in deafness. We know this can be a difficult time for you, and we encourage you to contact us as soon as you can. We believe in providing parents with full and unbiased information on all aspects of deafness and on the various services and options available to parents and children.

You may want to talk to other parents who have been in this situation, or to professionals who understand your situation, who will listen to you and support you. Please contact your local DeafHear Resource Centre who can provide professional support to you and put you in touch with other parents and services.

Coping Strategies

Many parents have said that once they gained some knowledge of hearing loss, their child's communication needs and language acquisition, they felt more in control and not as fearful. So try and get as much information as possible from reputable sources and take the time to read and understand it.



If you want information or jargon clarified, write down questions you want to ask the professionals before each appointment and write a few notes on the answers they give you.

Take the opportunity to speak to other parents - family and friends do mean well, but there is nothing like talking to someone in a similar situation.

Do not be pressured into making a decision for your child, be sure that you have enough information to make an informed decision.

Remember your child doesn't know any different and will still want to do all the same things as their peers, it might just be in a slightly different way!



Coping With Diagnosis

Role of DeafHear.ie

Since 1964 DeafHear has campaigned for full equality in all aspects of life for Deaf and Hard of Hearing people, and for parents of Deaf children to have appropriate support and services for their children's development.

DeafHear believes that Deaf children should achieve the same level of attainment as hearing children with similar abilities. While this has not always been achieved in the past, earlier diagnosis combined with appropriate early intervention support can support parents and children to make this a reality. It is DeafHear's principal aim to support and encourage parents and other stakeholders to make this a reality.

Family support services

Many parents experience a range of emotions when they discover that their child has a hearing loss. DeafHear provides a range of supports which you may find helpful at this time. The Family Support Service is a service for all parents of children with hearing loss, and focuses on helping individuals and families deal with their particular difficulties.

This service is available to provide support on a range of issues including coping with diagnosis, adjustment to deafness and hearing loss, behavioural issues, parenting, rights and entitlements, information and advice, social work and counselling, family therapy, personal and relationship difficulties, and advocacy.

DeafHear's Family Support Service comprises of professionally qualified Social Workers and Family Support Workers who are familiar with all aspects of deafness and hearing loss. This service is strictly confidential and is provided free of charge and through the communication method of your choice, i.e. Irish Sign Language, Lip-reading etc.



Information weekend for families with a child newly diagnosed with a hearing loss

The weekend brings families together from across the country, giving them the opportunity to gain information about supports available locally and nationally from professionals and peers. The weekend is led by experienced DeafHear



staff. The programme includes guest speakers with relevant experience of working with children with a hearing loss, such as an Audiological Scientist and a Speech and Language Therapist. There is a session with a Deaf person and their family members: they talk about their experiences of being a Deaf child in a hearing family and having a Deaf child in the family.

There is also ample opportunity to talk to other families and DeafHear staff. Parents of a child with a hearing loss have often said it helps to talk to other parents who have been through a similar experience to their own.

Resource centre activities

Each DeafHear resource centre has a programme of activities for families designed to provide information and support, as well as the opportunity to meet other parents and children. Activities include:

Family Fun Days - Easter, Summer, Halloween, and Christmas - these events aim to bring families together socially, giving ample opportunity for you to talk to other parents and for your child to meet their peers with a hearing loss.

Summer Camps - these are usually 3-day events and provide an opportunity for the child with a hearing loss and their siblings to meet other children in a similar situation to themselves in a fun environment.



Coping With Diagnosis

Professionals that may be Involved in Your Child's Life

Audiological Scientist - Audiologist

- works to diagnose hearing problems in children using a series of tests. They address hearing loss by the prescription and fitting of hearing aids and other assistive technologies. The audiological scientist works in the community and in hospital settings. Referral to the audiology department is usually through the Public Health Nurse or your GP.

Speech and Language Therapist

- can be involved with children who have any degree of hearing loss. They work with the child and parents to promote the development of communication and are usually located in local community clinics. The therapist will initially carry out an assessment in conjunction with the child, family members and other relevant professionals. Following the assessment the therapist will devise an Individual Therapy Plan, which should include aspects of development such as play skills, listening skills, turn-taking, comprehension and oral communication.



Ear, Nose and Throat Consultant

- (ENT) is a specialised doctor trained in the health, medical and surgical treatment of the ears, nose, throat and associated structures of the head and neck. They are based in hospitals and work as part of a multi-disciplinary team.

DeafHear Support Staff

- provide services to Deaf and Hard of Hearing people and their families. Our attention focuses on helping individuals and families deal with their particular situation. The services are strictly confidential and are provided free of charge.

Visiting Teacher for the Deaf and Hard of Hearing Service

- this service is provided by the Department of Education and Skills from the time of referral until transition to third level or further education. The aim of the service, through partnership with home and school, is the successful development of the whole child on an educational, social and emotional level. The visiting teacher covers a particular geographic region and supports the child, family, teachers and other professionals involved. The nature and frequency of the support will depend on a range of factors including the age of the child, severity of hearing loss, educational placement and individual learning needs. The visiting teacher provides information to parents and guardians on hearing loss, advises on the management of hearing aids, other assistive technologies and on all available educational options, enabling them to make informed choices for their child. Their main focus is on the development of language and communication skills in spoken and/or sign language (ISL).

Cochlear Implant Team

- this service is located in Beaumont Hospital, Dublin. The Cochlear Implant (CI) Programme is comprised of a multidisciplinary team of highly trained and qualified professionals specialising in deafness, including ENT surgeons, audiological scientists, speech and language therapists, teachers of the deaf, psychologists, and administrators. Assessment for CI suitability is carried out from a few months old and across all age groups. Once a child is assessed as suitable for a CI, and cochlear implant surgical intervention is chosen as the management option by the parent/guardian, the CI programme provides lifelong management for CI recipients residing in ROI. This includes individuals transferred from other programmes worldwide. The programme is completely publicly funded and includes assessment, hearing aid fitting, surgical intervention and all post-operative follow up and management. Referrals are accepted from any medical or healthcare provider.

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