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Hyperacusis in Children

This factsheet has been written for the parents or carers of children who have been diagnosed with hyperacusis, or who feel they are unusually sensitive to sound. It may also be useful for professionals (such as support workers or special needs teachers) who encounter children with hyperacusis through their work. The factsheet covers the following topics:

- What is hyperacusis?
- How can the symptoms be managed?
- How important is it for parents and teachers to understand the condition?
- What is behavioural desensitisation?
- What is auditory desensitisation?
- What research is being conducted into hyperacusis?

WHAT IS HYPERACUSIS?

Hyperacusis is the medical term used to describe abnormal discomfort caused by sounds that are tolerable to listeners with normal hearing. It is an elusive phenomenon. Because it is a subjective experience it cannot be measured directly and is, consequently, very difficult to study.

Hyperacusis should be distinguished from another, better understood phenomenon called ‘recruitment’. Recruitment is commonly associated with hearing loss caused by damage to the sensory cells of the inner ear and occurs because, although weak sounds cannot be heard, louder sounds are perceived at their normal level, causing discomfort and pain. Many people who experience hyperacusis have no detectable hearing loss, although it can be linked with other hearing problems such as tinnitus and Ménière’s Disease.

There are probably a number of different causes for hyperacusis, but recent research indicates that one cause may be a reduction in a brain chemical that controls the amount of information arriving at the brain from the sense organs. For this reason it may occur with visual over-sensitivity, or photophobia, as seen in migraine sufferers.

Hyperacusis may follow a blow to the head or exposure to loud noise but, for many people, the onset is sudden and inexplicable.

It may occur independently of any other identifiable disorder. However, hyperacusis is a recognised symptom of several conditions. Aside from tinnitus and Ménière's Disease, hyperacusis is sometimes also associated with post-traumatic stress disorder, migraine, some types of depression, vitamin B6 deficiency, Tay-sach's Disease and post viral fatigue syndrome (or ME).

It is particularly prevalent in people suffering from a genetic disorder known as Williams Syndrome. Other symptoms of this condition are failure to thrive in early life, developmental delay, cardiac problems, small stature and distinctive facial characteristics.

Not all sounds cause adverse reactions in hyperacusis sufferers. It may be a feature of the sound rather than its volume that causes distress. Electrical and machine noises seem to be amongst the sounds least well tolerated. People with hyperacusis may describe the sensation caused by particular sounds as 'painful', 'startling' or 'anxiety producing' but it is still not clear why individual sufferers are disturbed by some sounds while other, often louder sounds, do not cause problems.

For children, common sounds such as those from a washing machine or people clapping can cause extreme distress. At school, background noise can make concentration very difficult with subsequent poor achievement. However, unlike many adults affected, most children will find that the problem lessens with time.

HOW ARE THE SYMPTOMS OF HYPERACUSIS MANAGED IN CHILDREN?

There are a number of treatment strategies for children with hyperacusis, but most will involve elements of the five-step programme described below:

1. Profile of hyperacusis in the child's everyday life
2. Evaluation of impact of the problem on individual/family/others
3. Understanding of the condition by all carers (leading to consistency in the approach to managing the condition)
4. Behavioural desensitisation
5. Auditory desensitisation

The programme will normally conclude with a follow-up and assessment element.

HOW AND WHY IS A PROFILE OF THE CHILD DEVELOPED?

The hyperacusis management programme will usually begin with the gathering of information on the way over-sensitivity to sound is affecting the life of the child and his/her family, usually derived from careful discussion with the family and other carers. The aim is to identify the different factors which trigger the adverse reactions to sounds.

Although treatment will be based around the five-point plan, not every child will need all levels of intervention – the child's profile of responses to sound will help determine how the programme should be adapted to fit the needs of the child and the family. Often an explanation of the hyperacusis and subsequent behaviour patterns will indicate specific changes which need to be made to the child's environment, aimed at reducing exposure to certain noises.

HOW IS THE IMPACT OF HYPERACUSIS ON THE CHILD'S LIFE EVALUATED?

Diary sheets are often used to record the sounds that the child finds uncomfortable, and the times and places where these were experienced. These diaries, lasting a week, can be helpful in enabling parents and teachers to identify potentially uncomfortable situations for the child. The diary should not be kept for longer than a week as it may become a negative focus of attention for the child.

Wider discussions will also allow different people involved with the child to develop an understanding of the specific types of sounds which cause problems. Through this information, it should be possible to determine how tolerable certain types of sounds are to the child.

HOW IMPORTANT IS IT FOR PARENTS AND TEACHERS TO UNDERSTAND THE CONDITION?

Children with hyperacusis can often feel isolated and misunderstood, so it is important that adults understand the nature of the condition and how it affects the child.

Many parents are relieved to know that hyperacusis is a recognised condition, both in adults and children, and that it not a figment of their child's imagination or the result of attention-seeking. Parents are often given written information on the condition and encouraged to play an active part in developing strategies for helping their child cope with noise. If hyperacusis is not impacting on the child's life significantly, this may be sufficient.

It is vital that parents, teachers and all other carers of the child are consistent in their way that they respond to the child when an uncomfortable sound occurs.

It is also important that adults learn to understand that, for the child with hyperacusis, exposure to noise can cause actual physical pain – it is not enough to view hyperacusis as simply a phobia of noise.

WHAT IS BEHAVIOURAL DESENSITISATION?

Adults with hyperacusis often describe hearing noise as feeling like 'knives through the head'. The pain can trigger panic and can lead to anxiety and stress. They also describe the condition as isolating, and the inability of others to understand their

hyperacusis can lead to depression and withdrawal. For a child with limited communication skills, that feeling of isolation can be even more intense.

In order to break down the child's association of anxiety with noise exposure, a desensitisation programme may be necessary. A clinical psychologist can develop a programme of behavioural desensitisation, but the following suggestions can be used by everyone:

1. When the child becomes distressed by exposure to sound, move him/her away from the sound (if possible) and comfort them.

2. Try to explain the source of the sound to the child.

3. The child's fearful reaction to the sound will often diminish if s/he can exercise some control over the noise. Encourage the child to clap his/her own hands, to play with toys that make a noise and to stop/start the vacuum cleaner at home.

4. Repeated gentle exposure to the noise may help to reduce the child's anxiety and desensitise them to the sound. Tape record a number of the uncomfortable sounds and play them with the tape recorder set to a very low volume. Gradually, over a period of days or weeks, the volume can be increased. Practice with the sounds while playing, in a way that the child can control. By exposing the child to sounds in controlled conditions, the association of noise with fear can be gradually broken.

5. Children should not be forced to stay in a situation that is obviously causing them distress (for example, singing during a school assembly). This may compound their apprehension and make them associate a situation with pain. If fear of a specific situation has become established, it is important to gradually desensitise the child, with time and care.

6. Older children may be reassured if they are told they have the teacher's permission to leave the classroom for a few minutes at any point if they are exposed to an adverse noise. Children can be greatly reassured that they can leave a room, for a short time, if noise becomes distressing to them.

7. The use of ear plugs, muffs or defenders should be avoided except in extreme or short-term, unavoidable situations. Exposure to normal and tolerable sound is crucial if the ear and brain are to establish normal sensitivity.

WHAT IS AUDITORY DESENSITISATION?

Auditory desensitisation aims to reduce the over-sensitivity of the hearing system to the sounds that the child finds uncomfortable. If this is a very specific sound source, it may be easy to design a list of noises with which the child does and doesn't cope well – sounds that are less easy to categorise can prove more difficult. A tape recording of sounds played by the child at their own comfortable level may be helpful. In some cases, this approach may be undertaken by the family, without requiring professional support.

Noise generators and auditory desensitisation

Noise generators may play an important part in the auditory desensitisation process. These small devices look like hearing aids and produce a steady, gentle noise with a volume control, allowing the noise level to be turned up or down.

The aim of using noise generators is to improve the child's ability to tolerate normal exposure to sound by reducing the sensitivity of the ear. Although wearing the noise generator can mask the uncomfortable sounds, the device is intended to provide long-term, low-level noise exposure whilst maintaining normal exposure to everyday noise. There is no possibility of damage to the hearing through the use of a noise generator and benefits have been shown even when the generator is not in use, with longer-term improvements in the child's over-sensitivity to noise. Most adults using a noise generator report that, over a period of around one year to eighteen months use, hearing sensitivity becomes much more normal.

This is an established method of treating hearing over-sensitivity in adults and is used in many audiology departments in the UK. Using this technique with children, particularly those with learning disabilities, requires time and support, but has been found to be very effective, even for children with limited communication skills. There should be someone in your local audiology department who is able to advise you on the availability of this technique.

Hyperacusis can be managed most effectively by using noise generators in parallel with a programme aimed at reducing the fear and anxiety associated with sound exposure.

Fitting the device

Noise generators are worn behind the ear in a similar way to a hearing aid. The sound is fed into the ears through an ear mould which is specifically designed not to block the ear canal, allowing background noise to be heard normally. The ear mould and device must be comfortable and secure so that it is possible to build up the number of daily hours of use over time in comfort. As hearing sensitivity usually occurs in both ears, both ears will usually be fitted.

Setting the volume level

The device has a volume which should be set at the beginning of the day or in a quiet situation when the child is calm and relaxed. The child must be able to indicate when the sound level is just audible. The sound should not be intrusive in daily activity and, even if the background sound levels increase to a level that the noise generator can no longer be heard, the volume setting should remain the same. Only if the background noise level is uncomfortable to the child should the volume be increased to cope with the discomfort.

Daily duration of use

The aim is to build up the length of time the device is worn to at least six hours a day. This will usually be in the home in quiet situations, but will gradually include other environments such as at school. As the child becomes accustomed to wearing the device, it may be helpful for parents to keep a short-term diary of use and its

perceived effects. This will help parents to monitor changes in behaviour or the reaction to sounds while the noise generators are being used.

Increasing the volume
When the child has been using the noise generators quite comfortably for six hours or more a day without any problems, the level of the noise output should be fractionally increased. The new level should not cause problems for the child, though s/he may need time to adjust to it. Again, when s/he is able to easily tolerate the new level, the sound level should be increased. This gradual increase in output should be used to improve the child's ability to tolerate different environments in everyday life.

There is no set level that the child must reach, but when s/he can tolerate all the typical noise situations with the generators on, there is no need to continue to increase volume levels.

In practice, with the children who have been fitted to date, there has usually been immediate acceptance of the maskers, and they have quickly got used to the volume change.

After a period of use, you may find that there are situations that the child can now happily tolerate without the use of the masker – but don't over-challenge your child with situations s/he is nervous about. Only when the child can clearly cope with all circumstances without their maskers is the process complete and the brain's 'volume control' mechanism reset.

How long will it take?
Typically after using noise generators for 12 to 18 months, most adults find a long-term improvement in their sensitivity without the need to use noise generators. Although it is impossible to predict how long the process will take in children, the desensitisation should still be carried out over a finite period of time, set by the consultant or audiologist.

WHAT RESEARCH IS BEING CONDUCTED INTO HYPERACUSIS?

Thanks to the work of Deafness Research UK, real breakthroughs in understanding the nature of hyperacusis are being achieved, raising awareness of the previously unknown scale of this distressing condition. Though its subjective nature makes hyperacusis difficult to quantify, recent research suggests that up to six per cent of all children are affected by the condition. Researchers are now focusing on the possibility of developing new drug-based treatments for hyperacusis.

FURTHER INFORMATION

If any of your questions concerning hyperacusis have not been answered by reading this factsheet, contact the Deafness Research UK Information Service for further assistance. Our Information team will either answer your enquiry directly or refer it to one of our scientific or medical advisers.

Open: 9.00 a.m. to 5.00 p.m., Monday to Friday (a message can be left at other times)

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Deafness Research UK is the only national medical research charity dedicated to helping people with deafness, tinnitus or other hearing problems.

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