

## **The Sound of Guy Fawkes and Beyond**

### **Introduction**

Today approximately 1 in 150 people are diagnosed with autism. Parents are usually the first to notice unusual behaviors in their child or their child's failure to reach appropriate developmental milestones. Whether the child has had difficulties from birth or whether they have suddenly lost skills, it is very common for these children to have a strong sensitivity to sound.

At this time of year when Bonfire Night is approaching, the issue of sound sensitivity increases with each firework that explodes at a moment's notice and round every corner. Society worries about the effect of fireworks upon animals but what the impact upon the life of a child with autism and their family. In many, anxiety levels increase leading to more behavioural outbursts. However, in contrast, there are many children with autism and aspergers syndrome that tolerate and even enjoy fireworks, but are unable to deal with sounds like hoovers, etc. Whether this is due to the colourful firework display "cancelling out" the noise or it being the right type of noise who knows. Whatever the reason, sound sensitivity can be a huge problem for those with autism or aspergers syndrome. The following article, although not an exhaustive list, aims to provide the reader with some ideas about overcoming this issue, both generally and concerning Bonfire Night.

## The Way Forward

Far from being senseless, many people on the autistic spectrum have great difficulties with sensory integration. The most common of these, and often the most problematic, is sound sensitivity. In fact between 70 and 85 per cent of people on the spectrum have an extreme sensitivity to specific sounds. Although there are specific types of noise sensitivity (See Box 1) the general lack of control with filtering sound, distractedness and difficulty with spoken

1. **Hyperacusis** - In the most common form of hyperacusis, cochlear hyperacusis, the symptoms are ear pain, annoyance, and general intolerance to any sounds that most people don't notice or consider unpleasant. In extreme cases, sufferers may need to isolate themselves from sounds altogether. Hyperacusis may lead to episodes of crying or panic when noise levels reach a certain decibel. Hyperacusis in children may lead some doctors to misdiagnose them with autism. While this is a component symptom of autism, not every child who suffers from hyperacusis is autistic. Only by looking at additional symptoms can the varying diagnoses be teased out. Children suffering from hyperacusis may also experience nausea, instability and dizziness when exposed to certain sounds.
2. **Recruitment** - More common than hyperacusis is the sensitivity called recruitment. Recruitment occurs in people who also experience some amount of hearing loss. While they may not be able to hear certain sounds at certain levels, once the sound reaches a level where it can be perceived, a person suffering from recruitment can find themselves suddenly overwhelmed. Of course, being overwhelmed can manifest itself in numerous ways including the responses listed for hyperacusis.
3. **Hyperacute Hearing** - The Hyperacusis Network defines sufferers of hyperacute hearing as "individuals who are sound sensitive at birth but it is only specific to certain frequencies heard at loud levels (typically above 70 decibels)." Autistic children provide a useful example of this type of hearing disorder. While many sounds may be acceptable to them at varying levels of loudness, other sounds can set off outbursts and other indications of discomfort.
4. **Misophonia** - Misophonia is an extremely strong dislike of normal sounds. The degree of reaction is not based on the properties of the sound, such as loudness and pitch, but by past experiences with certain sounds and overall state of mind. This last category can often occur in concert with other hearing sensitivities such as hyperacusis.

### Box 1. – Types of sensitivity

instructions frequently result in restlessness, impulsiveness, behavioural difficulties and melt downs. How many times have you walked into a High Street shop with fluorescent lights and your child has placed their hands over their ears whilst screaming. Or have entered a noisy room full of people and screamed, but then another time entered a different crowded room without screaming. Apart from living in a sound proof room, what else can be done?

Noise is everywhere, even in the quietest of rooms. The sound of a ticking clock, the creaking a house makes and even the gentle breeze. Unfortunately unless you can find a sound proof room, noises are there. In fact removing all anxiety provoking noises rather than dealing with the situation has an adverse effect upon the child as they never learn to handle the problem themselves and are then reliant upon you as a parent for the whole of their lives. The important issue is to understand how sensitivity affects the person. Although it is difficult to empathise how noise effects a person with autism, an appropriate

comparison could be that of listening to the noise of fingernails scraping down a school blackboard. Although, as individuals, we would react differently it would still provoke a reaction from most of us. So if the mere thought of this puts a shiver down your spine, then consider how your child with autism may react to it as well as everyday noises. To further illustrate this, the following quotation was made by Temple Grandin:

*“Loud sudden noises still startle me. My reaction to them is more intense than other people’s. I still hate balloons, because I never know when one will pop and make me jump. Sustained high-pitched motor noises, such as hair dryers and bathroom vent fans, still bother me, lower frequency motor noises do not.”*

*(Grandin, 1988)*

Just imagine the barrage of noises and sounds that occur in everyday life, or those noises like the blackboard scenario that can cause pain for someone with sound sensitivity. However, although difficult to imagine, there can be a positive side to having these difficulties. For example, being able to hear a train before anyone else can, or utilising sensory “tune out” allowing the person to switch off or tune out specific sounds, as described by Temple Grandin:

*“When I was confronted with loud or confusing noise I could not modulate it. I either had to shut it all out and withdraw, or let it all in like a freight train. To avoid its onslaught, I would often withdraw and shut the world out .As an adult I still have problems modulating auditory input. When I use telephones at the airport I am unable to screen out the background noise without screening out the voice on the phone. Other people can use telephones in a noisy environment, but I cannot, even though my hearing is normal.”*

*(Grandin, 1988)*

The latter issue of sensory “tune out” is frequently perceived by those around the person as deafness rather than a coping mechanism. Donna Williams described that:

*“My mother and father thought I was deaf. Standing behind me, they’d take it in turns to make loud noises without so much as a blink in response. I was taken to have my hearing tested. The test showed I wasn’t deaf, and that was that. Years later, I had my hearing tested again. At the time, it was found that my hearing was better than average, and I was able to hear some frequencies that only animals normally hear. The problem with my hearing was obviously one of a fluctuation in the awareness of sound.”*

*(Williams, 1998)*

Once you have a clear understanding about the impact that sound sensitivity has upon the person it is essential to ascertain what is happening with your child’s own situation. Unfortunately this is the difficult part as it relies heavily on the child’s observable behaviour (the consequences of the sound sensitivity) and surrounding environmental factors at that time. As with any issue relating to behaviour, it can be as much a guessing game as it is a “scientific” approach, but by closely observing and recording what is happening when the behaviours are exhibited it is possible to gain a better picture of the situation.

### **Strategies to reduce sound sensitivity**

So evidence and your gut feeling seem to indicate that sound sensitivity is an issue for your child, how do you progress? Obviously noise cannot be eliminated from life. When it reaches certain levels it can be dangerous to anyone though (I still remember running to my room after hearing my first firework, luckily the mud on my boots came off the bed sheets) and for some with autism that level is reached at a different point because they are particularly sensitive to noise. Firstly it is important, whilst developing practical approaches, to consider the possibility of a physical cause to the situation such as glue ear or some form of infection which needs to be resolved. This can be done with the help of a GP or Paediatrician.

When practical strategies are needed how do you help your child to deal with all the environmental sounds and noises, especially with the imminent arrival of Bonfire Night. Before providing some practical approaches it must be highlighted that the initial use of any

approaches must be done in a relaxed atmosphere. By doing so, your child's tolerance in dealing with the sensory difficulties is much higher when dealing with the new approaches. Also as there appears to be some connection between the level of sensory tolerance experienced by a child with autism and their anxiety levels, by introducing approaches in such a way reduces this anxiety. Now that the atmosphere is as relaxed as you can make it let's look at the practical strategies especially keeping Bonfire Night in mind:

- **Avoidance**

Yes, avoidance as been mentioned in relation to not avoiding noises; however it can be a way forward for some. The aim is to recognise which sensory situations cause most difficult and anxiety for your child, and be prepared to allow your child the chance to avoid it. This works best with non-essential situations, such as not attending a firework display when your child hates the bang of fireworks. Unfortunately when this is not so then avoidance should not be utilised, e.g. a school not using a bell to indicate end of lessons because it affects a child with autism. In this instance, there will be numerous times in a person's life that a bell maybe rung, as well as probably impracticalities when going from primary school to high school. In these situations, further work is required.

- **Desensitisation**

This is best done when the anxiety levels are low and tolerance levels are high. The aim is to gradually desensitise your child to the stimulus that they find most difficult, for example if there are issues with hoovers then pick a moment when your child is happy, calm and confident and then turn the Hoover on for short periods of time and at a distance. Both of these elements can then be adjusted to increase your child's tolerance levels. Each occasion of this happening should feel successful to both them and you, and should involve praise and congratulations in their ability to cope. Remember do not push the limits to fast. In relation to Bonfire Night, consider utilising the television or computer to show a firework display whilst slowly increasing the volume level so that the child's ears and processing abilities are not

shocked but can slowly adjust to the noise. Of course, eventually they will have to face the inevitable firework display but they will have a better idea about the whole situation. Desensitizing takes a bit of time and energy but for the autistic child's comfort it is well worth it.

- **Social Stories**

Even with sound sensitivity social stories can be used. As with any social story, one for this issue needs to give the facts about the problem and some form of definite ending. For example, if your child has issues relating to fireworks then a story can be compiled that discusses what is involved as well as allowing the parent to talk with the child to explore what the issues are.

- **Barriers**

Probably one of the most immediate strategies available would be some form of barrier to reduce levels of auditory stimulation. Barriers range from silicone ear plugs, ear muffs and noise reducing headphones. The choice of barrier will depend upon your child and their specific situation. Silicon earplugs are useful for those that are able to judge and recognise the need for them. The earplugs can be easily carried around in pockets and inserted easily when required.

Ear muffs (ear protectors) and headphones are a more common method used to reduce auditory stimulation. These headphones are speakerless headphones and provide a way to reduce the overall sound exposure to anyone with a sensitivity to sound. These headphones do not provide complete silence. You can still communicate with your child and your child is still aware of the sounds around them. The sound is just reduced making it less disturbing and disruptive. Some “noise cancellation headphones” use batteries to power an electronic monitoring system which listens for ambient noise and attempts to produce a “canceling” sound wave inside of the ear cups. This style of noise cancellation is only effective for consistent,

rumbling noises such as electric fans, and airplane engines. They are not effective for cancelling spiky noises such as voices, and phones ringing. For people with auditory sensitivity, this style of noise cancellation is actually more harmful as the distracting noises such as shouting, alarms, or ringing phones are actually accentuated by the removal of the other ambient noise. The Direct Sound headphones work differently. They do not use batteries. Instead, they work by physically blocking all types of sounds from reaching your ears. The Extreme Isolation Headphones reduce all sounds, both consistent, rumbling sounds as well as spiky noises. Wearing these headphones is like closing yourself off in another room. You can still hear background sound but the sound is significantly reduced.

Of course ear muffs and headphones are more conspicuous than earplugs, but do allow others to put them on the child without any physical damage (e.g. pushing them too far into the ears). As previously highlighted, it is important to remember that the introduction of a barrier should be gradual and calmly done. So if considering using them for Bonfire Night, start introducing them now before the big event arrives.

- **Integration Therapy**

There are two main therapies that have been shown to help reduce auditory sensitivity in children with autism and Aspergers Syndrome. Both require a trained professional to develop and co-ordinate the activities involved but also require commitment from parents to carry it out. The therapies are:

- **Sensory Integration Therapy** which was developed by occupational therapists and utilises a range of specialised play equipment to improve the processing, modulation, organisation and integration of sensory information.
- **Auditory Integration Therapy** which requires the child to listen to a number of hours worth of electronically modified music through headphones over a number of sessions.

Unfortunately the accessibility of either of these therapies through public sector organisations can be difficult and so frequently they have to be accessed via the private sector. Parents wishing to access the therapies privately should research thoroughly before paying for them as the therapies can be expensive but beneficial if using a reputable therapist.

## **Conclusion**

The issue of sound sensitivity in people with autism and aspergers syndrome can prove to be life changing and limiting for all involved. To be able to help them involves fully understanding how hearing and interpreting sounds is as individual as the person themselves. It is not just the issue of volume but tones, types of sound and environmental factors that impact upon the situation. The journey to achieve some level of resolution is one of patience, innovation and small, quiet steps.

As with any such support and change, the short but intense work needed to make that change reaps long term and life changing benefits. Whether this is going to a firework display or shopping with fewer or no outbursts, it is worth the effort. Finally it is as important to remember that we all have our own individual tolerances and fears whether this is fireworks or something else. So sometimes the issue is not one of sensitivity or autism but more about the child's personality and character.

## **References**

Grandin, T. (1988) "Teaching tips from a recovered autistic." *Focus on Autistic Behaviour* 3, 1-8

Williams, D. (1998) *Nobody Nowhere: The Remarkable Autobiography of an Autistic Girl*. London: Jessica Kingsley Publishers.