Autism Unwrapped
#Autism Tips

Stella Waterhouse

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Introduction

If your child has been diagnosed with an Autistic Spectrum Disorder (ASD) there will no doubt be many times when you find yourself puzzled and concerned. This book aims to help you make sense of the many and varied difficulties such children live with on a daily basis while also giving you a number of tips, ideas and strategies that will make life easier for the whole family.

People with ASD often feel they inhabit another planet, which is why some refer to themselves as aliens. Certainly, judging by their reactions, they find this world both impenetrable and frightening.

Such feelings are often thought to result from the difficulties they have in relating to those around them, and their inability – regardless of intellect – to empathize with or communicate their emotions to others, in the way that most people do. Those ideas are reinforced by the diagnostic criteria which focus mainly upon the difficulties with social relationships and communication and/or unusual behaviors. Even so, those are just the tip of the iceberg.

To determine what underlies them we need to consider the accounts of people with ASD themselves who, time and again, talk of feeling "fear, terror or confusion" and of "unusual sensory experiences" which are similar to those found in children with other learning disabilities like dyslexia, dyspraxia or attention problems – albeit far more severe.

Some people, like myself, believe that those sensory differences also play a major part in ASD. Long known to researchers, most fall into three groups so that the child may be hyper (over) sensitive, hypo (under) sensitive or alternatively, a mixture of both – with vision being even more complex.

So how might those sensory differences affect the child?

Grow up anywhere in the world and, while the language and climate differs, much remains the same. From birth, the majority of us can see our parents and hear their voices, using all our senses to learn about the world around us.

Initially we learn to associate pleasure and comfort from the warmth, touch, feel and smell of our mother. As we grow we play with our food, enjoying its feel as much as its taste and texture. We have fun playing peek-a-boo and other games with our parents, "exploring" our toys and the objects around us with all our senses.

When we are hurt we get comfort from our mother's touch and find her voice soothing. In short we also use our senses to learn about relationships, the wider world and our place in it.

Imagine though, growing up in a different way, where nothing is quite as it seems. You are not blind but you cannot see properly (although those around you assume you can). Your mother is just a large blob moving towards you; her outstretched arms may even look quite threatening…although you can recognize her when she gets close. People frighten you for their faces are disjointed and change when they move.

However careful she is it hurts when she cuddles you or brushes your hair. Things sparkle in the air. They distract and fascinate you. Some of them smell overwhelming – of toothpaste, perfume, dogs, smoke and more.

You may find it hard to hear things or find some noises really loud and immensely frightening, like dragons breathing fire… Background noises impinge on you all the time and stop you from hearing properly when people are talking. Your mother's voice is drowned out by the street noise…

This is the world inhabited by the child on the autistic spectrum; who experiences the most bizarre sensations. Hardly surprising then to hear such children and adults talk of confusion, terror and fear for those are the only constants in their world: things that leave them at a real disadvantage in understanding and coping with the world around them.

Please Note: *For ease of use the male pronoun is used to cover references to both male and female children. No gender preference is intended.*

A Visible Difference

Does your child play with the lights – flicking them on and off? Does he have a squint or "wandering eye?" Does he avoid bright lights or screw his eyes tight shut in some situations?

Or perhaps he is clumsy, dropping the cup when he tries to put it on the table – and then surprising you by finding some tiny glittering object buried in the carpet that is invisible to you? Or stuff his pockets full of tiny things that look drab and boring to you?

If so the answer may lie in his vision.

Vision accounts for over 70% of the information we receive about the world and is extremely important to learning.

Many children with ASD suffer from specific visual problems (which are not generally identified in an ordinary eye test). These are similar to the problems found in visual dyslexia (also known as Irlen syndrome) but are far more severe.

Unfortunately, despite having wide ranging effects that mean that, quite literally, the child **does not see what you see**, such problems frequently remain undiagnosed: leading to anxiety, frustration and poor self-esteem.

These visual problems include a range of focusing anomalies so that the child may not be able to coordinate his eyes properly or has a "wandering" eye or a squint. He may also have poor visual acuity or photo-phobia (which is simply a physical "over-reaction" to glare, brightness or fluorescence) that is outside his control.

The effects of such anomalies are individual but when mild to moderate can include clumsiness and poor writing; as well as headaches or migraine when under bright or fluorescent lights.

Reading can also be problematic as the child may see a variety of visual distortions. It may look as if the letters are moving or jumping off the page or one sentence may suddenly look like two or it may seem as if the text has white rivers running through it.

Such problems are not always obvious in the early years when books have large, well-spaced, print but as the child progresses through school, the print and the spaces between the lines decrease in size, making it harder for him to read clearly.

For many children with ASD the severity of the problems also means that they may experience a variety of effects that could include:

- problems judging differences in height or width – which are often particularly noticeable when he steps off a curb or over a threshold.
- difficulty following moving objects – so he may not see an approaching car until it is very close.
- double vision; seeing two separate images at the same time.
- fragmented vision – so that faces may seem distorted and all he sees clearly may be an eye, a mouth or an earring.
- a confused perception of space and size – with objects changing size or shape at times.
- some things may seem magnified – one child saw a hair as if it were a strand of spaghetti – which can lead to a fascination with tiny things and make him good at doing intricate tasks

Any child who sees in this way is actually only partially-sighted; living in a world where nothing is quite as it seems, nothing is constant; where other people (and objects) can, at times, appear to be extremely frightening. Even so there are several ways in which you can alleviate the worst of these effects.

Top Tips

- Fluorescent lighting and bright lights can aggravate visual problems. If possible, eliminate them from your home and use other more suitable lighting – like uplighters.
- When in situations (like shops/school or outdoors) encourage him – or her – to wear sunglasses/tinted lenses** or a peaked cap to minimize the effect of bright sunlight, glare or those fluorescent lights.
- Explain the reasons for this to his teachers so that they realize the benefits.
- Minimize obstacles for him and don't rearrange furniture, etc., as this could confuse him.
- Help him to find things easily by using dark or brightly colored items in the house.
- Use colored towels and a different colored toilet paper for easy identification.
- Color bath water, as some children have difficulty seeing things that are clear, especially under bright lights, but be careful if adding anything smelly as that could cause problems too.
- Used toys designed for children with visual impairments.

****Tinted lenses**. The right lenses can help correct some of the visual anomalies, leading to number of benefits which can include better eye tracking and depth perception; a reduction in confusion and hyperactivity alongside improvements in the ability to concentrate, learn and remember things; improved behavior and increased confidence, sociability and communication.

Some professionals remain dubious of these but I have validated them through personal experience of mild visual problems, finding them very effective and I know of several people with autism who have also been greatly helped by them.

NOTES

Face Blindness – Who Are You?

Have you ever met someone that you couldn't quite place? Someone who you "know" you know but don't recognize them immediately because they are out of context: perhaps no longer wearing a uniform or in the place where you would usually see them?

An embarrassing situation but one that happens to most of us only occasionally. But how would you feel if it happened to you constantly? If you recognized your parents at home but inadvertently walked past them in the street?

That is the world that people with face-blindness live in each and every day of their lives. When severe it can result in an avoidance of social interactions, problems with relationships, anxiety and even depression.

That is also a world in which some people with ASD live as we can see from their accounts. Thus in her book *A Real Person – Life on the Outside* Gunilla Gerland, who has Asperger's syndrome, described seeing children with blank faces.

Nor is she alone in that for Donna Williams tells us how "complete strangers" used to smile or wave at her, some even calling her by name. Others too describe seeing only parts of a person such as a bald head, beard or earring; which may explain why some children focus on and are seemingly fascinated by such details.

School can be particularly stressful for any child who is face-blind.

That's because:

- He will not be able to identify other pupils (even after sitting beside, them for some time).

- He may confuse one person with another - and that could make the playground very frightening.
- He could also have difficulty “reading” facial expressions or body language correctly – which will make it very hard to distinguish friend from foe.

Sadly, his problems are often compounded by the fact that other children see him as arrogant or aloof because they mistakenly believe that he ignores them outside school – and that may make him a target for bullying.

Hardly surprising then that many such children learn to use other clues to identify people – like the way they smell, their clothes, the way they move or an identifying feature such as a mole, tattoo, beard and so forth.

Top Tips

- Explain face-blindness to him and to those who are in daily contact with him such as teachers/other staff.
- Ask the school staff to wear badges/lapel pins and to introduce themselves by name when speaking to him.
- If possible ask if he can have a class seating plan (with photos).
- A school without uniforms will make life easier.
- Always introduce people to him by name even if he already knows them.
- Suggest ways in which he can identify people – using the features which are least likely to change:
    - Voices/accents.
    - People’s body shapes, posture, the way they stand, their gait – or the way their clothes move as they walk.
    - Clothes – as people often wear distinctive styles.
    - Hats/coats/shoes – as people generally have only a few favorites.
- If you or someone he knows well alters something significant like a hairstyle tell him in advance if possible.

- If you do not have any identifiable marks wear a particular brooch/tiepin/ lapel badge – especially when picking him up from school.
- Teach him to say “I’m sorry, I don’t know who you are” if necessary.

Face-blindness (also known as prosopagnosia) used to be considered extremely rare but is now known to affect around one person in 50 to some degree. While it can be acquired through some type of brain injury, some children have what is termed congenital or developmental prosopagnosia, with the child being affected from birth.

Certainly developmental prosopagnosia runs in families and is thought to be particularly common among people with ASD who often also have some degree of developmental delay.

Pictures of faces are stored in a special part of the brain and in some cases, “face blindness” is caused by a malfunction in that part of the brain. Even so, there is a possibility that, for some children with ASD, face-blindness could be linked to the fact that the visual perception pathways are either damaged or have not fully developed; giving rise to problems photo-phobia or poor visual acuity.

Although research has yet to determine the answers, it is clear that if you cannot see faces correctly the only pictures you could store would either be blank or extremely bizarre: which would make remembering and placing faces almost impossible.

NOTES

Hyperacusis – The Torment of Sound

Does your child ever block his ears or suddenly run away? Or become very agitated and upset at mealtimes or in noisy situations. Or simply refuse to enter a building or go into the garden? If so the clue to his behavior probably lies in the sensory differences: specifically, his hearing.

The problem that causes such reactions is hyperacusis (hypersensitivity to sound), a painful and debilitating condition that can make some sounds seem louder than they actually are. Worse still the person is generally unable to block out the sounds that hurt and that can leave them tormented by various everyday sounds that most of us ignore or at least tolerate.

Much of the research into hyperacusis has been done with older people who have tinnitus and yet hyperacusis actually affects a wide range of people, some of whom, like myself, have had the problem since childhood.

Josephine Marriage, the former Head of Pediatric Audiology at Addenbrooke's Hospital, Cambridge, in the UK has a particular interest in hyperacusis. Her research showed that each person had individual sounds that they found intolerable, ranging from noisy washing machines and vacuum cleaners to relatively quiet sounds such as a tissue being taken out of a box, a newspaper being folded or a dog barking in the distance.

Similarly, in my informal research people identified a clock ticking in the flat next door, the hum of a fan, the sound of butterfly wings and even the noise of other people eating.

Nowadays everyone is aware of noise pollution but, unless they have experienced hyperacusis themselves, most people do not appreciate how devastating its effects can be. In fact, because this is somewhat obscure, some people are unaware they have it – although their nearest and dearest may recognize that they become irritable, short tempered and stressed in certain situations.

Those people who are aware of it may go out of their way, often literally, to avoid particular situations as with one man who, come rain or shine, went out for a walk every time his wife did the vacuuming. It can also affect people's social lives as they tend to avoid noisy situations preferring to be on their own or with just a few other people.

But when you cannot control your environment things become extremely difficult as with the unfortunately named Mrs. Fussy who finally took her neighbors to court because the noise from the birds in the aviary in their garden kept her indoors. Easy to laugh perhaps but if you have ever experienced anything like it you would know that hyperacusis can indeed make life a misery.

Perhaps some well-known sufferers can tell us how it feels? Writer V S Naipaul gave a clear indication of the distress such hyper-sensitivity can cause when he said how *"immensely happy"* he was when his hearing "*began to degenerate.*"

Similarly, Annie Proulx, the well-known and highly acclaimed author of "The Shipping News" and "Brokeback Mountain" to name but two, finds excessive noise hard to cope with, which may account for the fact that she lives in the wilds of Wyoming, real – isolated – cowboy country.

In an interview entitled Dirt Rich writer Marianne MacDonald shed some light on this fascinating woman, finding that Annie Proulx couldn't bear a lot of noise and that, as a kid *"the most dreadful sound in the world" was* her mom vacuuming.

No surprise then that hyperacusis has such a dramatic effect on children with ASD especially when they have no control over the situation they find themselves in – as at school.

Top Tips

- Ensure he or she has a quiet place of one's own where he or she can go when noisy things (like vacuuming, washing up, lawn mowing etc.) are going on.

- Try to determine which sounds she or he dislikes and the situations or places in which they occur. You can then encourage her or him to use earplugs or a MP4 player if appropriate so that one can cope more easily.

See page 23 for some suppliers of ear plugs and ear defenders.

NOTES

Other Auditory Differences – Do You Hear What I Hear?

Is your child terrified by loud noises? Does he speak in a rather unusual way – perhaps very quietly or too loudly or in a monotone? Or is his speech and language delayed?

Apart from hyperacusis there are several other auditory problems that can give rise to such things as we learn from the late Dr Carl Delacato in his book, The Ultimate Stranger and the late Dr Guy Bérard who detailed the technicalities of such auditory differences in his book Hearing Equals Behavior.

First to return to hypersensitivity, but not hyperacusis. It is clear that many children with ASD are super-sensitive, hearing things that most other people are unaware of, from the other end of a telephone call to the sound of a “silent” dog whistle: something that is often reflected by the fact that they speak very quietly.

Regardless of age, some of these children (like young children during early development), will also find loud noises very hard to cope with. This is the child who is overwhelmed by any unexpected loud noise – whether it be fireworks, thunder or traffic.

As Gunilla Gerland tells us in her book *A Real Person*, a moped revving so disorientated her that she felt as if the ground beneath her had disappeared and that she would either fall over or explode from the inside. Just imagine how absolutely awful that must be.

Hardly surprising then that many children have a “meltdown” or freeze on the spot when a fire alarm goes off suddenly – as with Raymond in the film Rainman.

Next to **hypo-sensitivity**; a mild deafness which is often overlooked – or even misattributed to autism.

And yet the signs are obvious once you know what to look for, for this is the child who is fascinated by noisy things like the washing machine and lawn mower, loves the sea and the noise of thunder. He also enjoys playing noisy games, banging, shouting, flushing the toilet, slamming doors, ripping paper – and more.

However, because he is not able to hear the rise and fall of your voice or the emotions it conveys, he may have problems learning to speak and, even when he does, his voice may be monotone and emotionless and/or be overly loud.

Then there is the apparently strange category of "*white noise*." This is the child who hears internal sounds as with one boy who said that his ears were noisy inside, making a constant "shushing" sound or the girl who said she could hear the blood flowing in her veins and the sound of her heart beating. Hardly surprising then that the auditory "fuzz" interferes with their concentration and their ability to learn.

Dr Bérard also identified a number of children who simply find it hard to hear some frequencies clearly and so "misplace" some letters and "mishear" words; making it sound as if other people are "talking nonsense."

This is the child who struggles to understand (or follow) conversations and has great difficulties learning to speak and communicate clearly. Sadly, such problems are compounded by seeing how easily other people understand each other and converse, thereby destroying his confidence and self-esteem.

Top Tips

- Identify the causes of his behavior.
- Share your knowledge with any teachers/other professionals who work with him.
- If he is hyper choose quiet toys.
- If hypo offer toys that make a noise – organizations that work with deaf children may offer ideas.
- If his hearing is very acute, make sure you don't talk about him unless you are absolutely sure he cannot hear you (unless you actually want him to hear).

- ☐ Give him some "noise protection" (headphones and music, earplugs, ear defenders) * during thunder storms etc.
- ☐ Remember that if he mishears things he will not necessarily be able to pin-point where sound is coming from and that can potentially be dangerous when near traffic.

* There are several types of soft earplugs on the market. Young children may like SpongeBob SquarePants Printed Earplugs.

* Level dependent or "active listening" ear defenders can filter loud sounds and sudden noises, while amplifying quiet sounds, so that the person can still hear conversations and alarms.

Amazon have a good variety of products but other suppliers include:

US & Canada

- http://peltorcomms.3m.com

UK

- http://theeardefender.com seems to have a good variety.
- http://www.onedirect.co.uk (mainly for adults)
- http://www.peltorheadsetsales.co.uk

Europe/other countries

- http://peltorcomms.3m.com - For a complete list of countries go straight to: http://solutions.3m.com/wps/portal/3M/en_EU/PPE_SafetyS olutions_EU/Safety/Resources/WhereToBuy/

NOTES

Auditory Processing Disorder – Lost in Translation!

Does your toddler mispronounce words, confuse similar sounding words or say "what?" time and again? Does he get very restless when stories are read, preferring to watch a video or do a puzzle?

Or do you have an older child who dislikes anyone talking (even quietly) when he is listening to the television? Or a child who dreads the embarrassment of reading in front of others? One who is often forgetful or finds it hard to verbalize his ideas and emotions?

If so there is a chance that he has APD (auditory processing disorder). Also known as Central Auditory Processing Disorder (CAPD) this umbrella terms covers a variety of disorders that affect the way the brain processes auditory information: and is often left undiagnosed because it does not show up on routine screenings or an audiogram.

Usually when we hear sound, that sound goes via the inner ear into the brain where it is translated. APD adversely affects the child's ability to correctly process and interpret auditory information (especially in noisy situations) so that although he hears the sounds, the end result is distorted or incomplete.

This is the child who finds it very difficult to recognize subtle differences between sounds or interpret speech correctly. That makes it very hard for him to follow or keep up with a conversation; something mirrored in his own speech which is often delayed or unclear.

At school he will find it exceptionally hard to learn things orally, have difficulty sounding out words or in learning to read, spell, write or do verbal problems. He may also find it very hard to follow auditory instructions, especially when several are given at once. Sometimes too he will just guess at words and that can lead him to misinterpret situations.

This is also a child who is unusually sensitive to sounds and/or finds loud or unexpected sounds difficult to cope with. A child who tends to interpret words literally and finds it hard to understand abstract information.

Unsurprisingly the child with APD will often lag behind his peers at school and, although generally of normal intelligence, if left untreated such auditory problems will eventually result in academic difficulties.

To make matters worse such things are often compounded by the fact that such a child is often easily distracted, disorganized and/or forgetful which can sometimes get him into trouble with his teachers who may think he has behavioral issues or simply lacks intelligence (neither of which are true.)

Interesting to see how many aspects of APD clearly overlap with some of other auditory differences already discussed and some facets of ASD. Perhaps it is no surprise that, like other developmental differences, the causes of CAPD are very varied.

Thus it can sometimes run in families or result from a difficult birth or illness or even a head injury, while in some instances the exact cause remains unidentified.

Top Tips

- Use simple sentences emphasizing key words.
- Slow your speech and, where appropriate, increase the volume slightly.
- Only give him one or two directions at a time and where feasible ask him to repeat them back to you.
- Where possible reduce the background noise – using sound-absorbent partitions, felt on chair feet etc.
- Provide him with a quiet place in which he can do homework.
- Encourage good eating and sleeping habits.

NOTES

Touch – The Princess and the Pea

Did your baby arch away from you when you held her or tried to feed her? Or your toddler rush away to avoid that hug?

Does she hate to have her hair combed or brushed? Or does she insist on wearing the same clothes time and again – or take them off at every opportunity? Such behaviors are not simply "autistic" fads. They arise from some degree of tactile hypersensitivity.

Those of you brought up on fairytales may remember the story of *The Princess and the Pea* in which the princess proved that she was of royal blood by being unable to sleep when a dried pea was put in her bed – hidden beneath 20 mattresses.

Unfortunately, such sensitivities are not confined to the realm of fantasy nor a sign of royal blood, but instead affect a whole range of people being most severe in people with ASD.

Sadly, that means that normally pleasant stimuli feel painful and, to make matters worse, go on and on and on, as the accounts of people with ASD themselves show – irrespective of where in the world they live, or their age or circumstance.

Thus in her first book *Emergence – Labelled Autistic* Temple Grandin gave a clear insight into her unusual sensory experiences. She talked about her longing to be touched and hugged even though she found such things physically painful.

She also gave a comical description of "one very, very overweight aunt" whom she liked immensely but who "*totally*

engulfed" her, causing her to panic because she felt "*it was like being suffocated by a mountain of marsh-mallows.*"

Then there is Donna Williams who in her first autobiography *Nobody Nowhere,* tells us that she hated being hugged because it "*felt like I was being burned.*"

Swedish author Gunilla Gerland also details severe problems in her autobiography *A Real Person: Life on the Outside.* Not only did her exceptional sensitivity stop her from showering – because the drops of water "had sharp little points that stabbed," but, from about the age of 8, she began to get a burning feeling on her head and neck so that whenever her hair was brushed or combed her hair and even the inside of her ears hurt.

Ros Blackburn too tells the tale of how she was sitting in a lecture when the handbag of a woman walking along the aisle behind her, brushed lightly against Ross back. The lightest of touches; like a feather. And yet Ros continued to feel that touch (and be distracted by it) for about three hours.

That hypersensitivity can also have unexpected results as we learn from an Italian man simply known as Alberto, an account of whose life forms part of Douglas Biklen's anthology *Autism and the Myth of the Person Alone.*

Alberto has spent his life " fighting sensorial distortions" something he illustrates this by telling us how hard it was to play a ball game with his mother. Why so? Simply because, although he liked the idea, the idea of touching anything – even a ball – was so awful that he simply froze. Imagine just how awful that must be.

Are there any compensations at all? Certainly that hyper-sensitivity can sometimes create a fascination (or even a fixation) with various textures from the links on a chain to other people's hair.

Even so such fascinations can be double-edged and have the potential to cause problems as the child grows up. Perhaps it is fortunate that by that time many people with ASD have developed ways of coping with their hypersensitivity.

Top Tips

- Make everyone in the family aware of his hypersensitivity.
- Do not hug her or him unless she or he is expecting it.
- Check that clothes do not have "prickly" labels or scratchy stitching.
- Work out which clothes he finds most comfortable and buy more than one of each item.
- Wash new clothes, sheets, etc. before use to help soften them – or buy specially manufactured soft/seamless clothes.
- Wear moccasins instead of shoes.
- Make putting dirty clothes in the wash and choosing clothes for the following day a bedtime routine.

NOTES

Hypo-tactility – Touchy Feely

Does your child enjoy being hugged? Or like a "rough and tumble?" Are you puzzled because he insists on contorting himself? And doesn't cry when hurt? Or does his behavior simply distress you – perhaps because he hits or bites himself? If so it is likely that he is hypo (under) sensitive to tactile sensations.

In an article on the AUTISTIC EAGLE website, Sam, a 16-year-old Aspie who lives in Australia, tells us what it feels like. He says that he "adores" touch and goes on to explain that because his sense of touch is severely limited he cannot really feel things properly unless he uses the whole of his hand or his arm.

Like most things, such hyposensitivity has both an upside and a down. The upside because, this child will enjoy physical contact with his parents. But not being able to feel properly has a downside for it also means that the person will not necessarily be aware if they hurt themselves.

And that leads us onto the subject of self-abuse, for this is the child who craves sensation and what begins as sensory stimulation can sometimes escalate until it becomes self-injurious – as with the child who bites or hits himself or picks at scabs so that wounds do not heal.

The late Svea Gold, writer, educator and lecturer, tells us about Janet. As she wrote:

> *I think I must have turned deathly pale when she finally allowed me to see her arms. They were covered with long slashes, some scabbed over, some still oozing blood. . .. As calmly as I could muster, I asked why she did it. "It calms me," she answered. "Well," I said gently: "This means you have no feeling in your arms or you could not do it. It would hurt too much!"*
>
> *. . . no matter what the weather was, wind, rain or even snow Janet came without a*

> *coat, or even a sweater.*
> *Now that I had seen her bleeding arms, it made sense that she never wore a coat. The same lack of sensation in her arms, gave her little differentiation between hot or cold. . ..*

Self-injury can have other causes too. These range from a response to pain, to a way of calming oneself (as Janet did), or even of expressing frustration or discomfort; behaviors that may sometimes evolve until eventually they are used as a way to avoid doing particular things.

Then there are those, like Donna Williams, who tells us she used self-injurious behaviors (and behaviors intended to shock or embarrass others) as a “test” – to see if she was actually real.

So is hypo-sensitivity always the underlying cause as Svea Gold thought? That is certainly true for many children – especially if they have other sensory differences. However, like exercise, self-abusive behaviors can stimulate the release of endorphins – which both block the pain and also induce calm – so that may be a factor too.

While on the subject of self-abuse it is worth noting that such behavior is sometimes involuntary. Certainly seizures have been associated with head banging, slapping the ears, chin and/or head, hand-biting, and even hitting one’s face with the knees.

Biochemical differences may also underlie some of the other problems as with the child whose repeated head-banging was associated with milk or the study that identified an association between eye-poking and low levels of calcium: something rectified by supplements.

Top Tips

Explore and rule out possible medical/dental problems which could include:

- ☐ Illness – like flu or infections.
- ☐ Pain – like earache, headache, toothache, period pain.
- ☐ Digestive problems.
- ☐ Seizures. Common triggers include:

  - Stress
  - Sensory stimulation (lighting, noise etc.)
  - Social stimulation (demands.)
  - Foods.
- If he is hypo-sensitive an Occupational Therapist may offer advice.
- Use sensory toys – like a rocking horse or toys that.
- Give him tactile stimulation – such as massaging his hands/feet.
- If the child is hurting himself in an attempt to shut out the world offer some alternatives. This could include listening to music or tapping/banging an instrument or even his own leg.

NOTES

Autism and Tactile "White Noise." Uncomfortable Feelings?

Does your child scratch himself frantically at times? Or suddenly seem to get the shivers? Or perhaps have an unexpected outburst of hitting or slapping himself?

In *The Ultimate Stranger* in the 1970s the late Dr Delacato described tactile "white noise." These were children whose skin itched for no apparent reason or suddenly had an attack of the shivers. Children whose skin would ripple and move with even the hairs on their arms standing up for a few moments before settling down again.

Children who were prone to have periods of calm but would then suddenly hit themselves almost as if there had been a "buildup" of sensation within their bodies that they felt "impelled" to release.

Today we also know, firsthand, that such sensations are individual, affecting various parts of the body in different ways and that they can be extremely painful.

In her book *A Real Person* Gunilla Gerland tells us that she experienced a strange and highly unpleasant feeling – like cold steel – in her spine when growing up.

This caused an almost constant shudder that got much worse periodically – at which point it became a constant torture. Carly Fleischmann too has equally strange physical sensations although in her case they made her legs feel as if they were on fire and a million ants were crawling up her arms.

So what could possibly cause such problems? In many cases such things are related to Sensory Processing Disorder (SPD) but other factors have been implicated too – especially in relation to itching. These include:

- Stress.
- Elevated histamine levels.

- Possible food allergies/intolerances.
- Possible allergies to soap products/shampoo etc.
- Side effects of some medications.

So how can they be alleviated so that the child does not scratch or hit himself until he bleeds, or continue doing such things until the behavior becomes habitual?

One of the most important factors with children is to find some way in which they can communicate so that they will be able to tell you how they feel and also share the things that help them feel better. There are a wide range of ways in which this can be done if the child is non-verbal from augmented communication to speech apps – a subject I'll return to later in this series.

Meanwhile the most helpful tips I have found so far for alleviating the problems (taken from a variety of sources) include:

Top Tips

- Keep a diary in which you can note the times/days the child seems most affected.
- If SPD is part of the problem an Occupational Therapist may be able to offer advice on the best ways to help the child. This could include.
    - Massage – it can relieve stress as well.
    - Rubbing or "brushing" his arms with a soft brush.
    - Drink plenty of liquids and eat a healthy diet.

If you have concerns about his diet get professional advice to see if he would benefit from removing food such as gluten and milk or food dyes/preservatives. NB If you stop milk do try to avoid substituting it with soy as many people are allergic to that too.

- Stress is a constant for children with ASD and can deplete his body of some nutrients so supplements may be needed too – but do take advice first.

Unfortunately scratching an itch causes the brain to release a chemical called serotonin to help control the pain – which tends to make the itching more intense.

Research into itching is ongoing but meanwhile other products which seem to have helped some children include:

- Non-allergenic soaps/shampoos and non-bio washing powders.
- A humidifier in the home can help alleviate dry skin.as can hypoallergenic moisturizing face and body lotions
- Lauricidin® a non-toxic product derived from coconut oil.
- Honey and Vitamin C.
- Quercetin – a plant pigment.
- Topical lotions – like Calamine, Sarna and Gold Bond lotion.
- Antihistamine medications like Benadryl, Claritin etc. but it is wise to check with your doctor or pharmacist first if using these.

NOTES

"Hyper" smell – Can You Smell That?

Did your child fight at the breast? Does he get upset or retreat when some people approach him – seemingly without reason? Or avoid certain places – even when they are quiet?

If so it is possible that he suffers from "nose pollution" (an extreme hypersensitivity to odors) which he will be unable to block out.

In the early days of life, the senses of smell, taste and touch are more highly developed than sight or hearing but as the child grows a change occurs and taste and smell are generally "relegated" to a secondary role. But life is actually pervaded by odors and while most of us have no problem with that any child who is hypersensitive to smell is likely, as the late Dr Delacato wrote, to live "in a horrible world."

Being "hyper" to smell can have far-reaching effects. Most of us might find it unpleasant to holiday near a farm where the farmer had been muck-spreading, but after a short time we would "shut the smell out" so that it no longer troubled us. Imagine though if that smell remained with you hour after hour after hour?

For hyper children things are much worse for it isn't only strong smells that are problematic. Some of them are so sensitive that they smell things that most of us could not detect.

To make matters worse many everyday products smell much stronger to them than they would to you or me – so that one man even hated to walk on the lawn because he found the smell of fresh grass intolerable.

That enhanced sense of smell is a gift to people who create perfumes (who are sometimes referred to as a "nose") and certainly some smells may be pleasurable for the hyper child and yet at other times that hypersensitivity is also a curse.

Just imagine yourself as an infant, whose mother has just picked you up. You suddenly become aware of a variety of strong and overpowering smells; a confusion of perfume, hairspray, soap and even her breath (and her breakfast) as she talks to you: some of which are extremely unpleasant! You could make more sense of faces if the people came close, but then … the smell! Your father's clothes smell of dogs and smoke and when he speaks smoke, coffee and toothpaste waft towards you and overwhelm you.

Hardly surprising then that some everyday smells lead such children to avoid the kitchen and even reject some foods because of the smell. Or that some children will do anything to avoid going to the toilet: a few being so sensitive that their own waste makes them gag or vomit. Or that such problems can severely limit social contact – as with the girl who "found" that "9 out of 10 people have halitosis."

Such things have been associated with ASD at least since the 1940s as we find in an account by a young man who was originally diagnosed by Kanner when he was 5. When he was 31 he described his childhood to the late Jules Bemporad, a psychiatrist. As Dr Bemporad recalled:

> *The recurrent theme that ran through all of Jerry's recollections was of living in a frightening world presenting painful stimuli that could not be mastered. Noises were unbearably loud, smells overpowering.*

Today we also know that some people have specific smells that actually give them headaches, stomachache, nausea, or even trigger seizures: one person finding that a whole range of smells including paint, cigarettes, glue, alcohol and yeast triggered his seizures.

Top Tips

- ☐ Explain the problem to those people he has regular contact with.
- ☐ Be aware of the products you use yourself.
- ☐ Alter the environment to decrease his discomfort by:
  - ■ Keeping household odors to a minimum and avoiding products that have strong odors wherever possible.

  - Using good ventilation to eliminate strong odors.
  - Using non-smelly soaps/deodorants/washing powders.
  - Keep food bland and non-aromatic.
- Get him used to tolerating smells but remember not to hold them too near him and always begin with very mild smells before gradually extend the range.

NOTES

Supertaste – Tasty? Or Nasty?

Has your child always been a picky eater? Does he stick to a few bland foods? Or push strong foods away – or even gag on them? Or detest bubbly drinks – and even some sweets? If so there is a good chance that he is "hyper" sensitive; perceiving tastes and flavors more intensely than many other people.

In this complex area there is also an interplay with two other senses. Thus whilst sensations such as sweet, sour, bitter, salty and umami (the fifth taste) are all related to taste, the other attributes of food, like its texture, feeling in your mouth and temperature are related to touch whilst its detailed flavor is related to smell.

The child with "supertaste" experiences tastes – and usually smells too – as being very strong. Thus sugar is sweeter, salt saltier, the fat in milk is creamier and bitterness is appalling. Strangely though, despite such sensitivity, such children often can't get enough salt – perhaps because it helps block out the dreaded bitterness? This child finds the sensation of bubbly drinks more pronounced – and can also distinguish individual flavors in a mixture very well: a skill some top chefs seem to share.

There can be a real downside to this as an article entitled "Are you a "supertaster"? in *The Guardian* newspaper tells us. Thus one woman talks of tasting the rubber from the utensils her mother used in cooking whilst the author, Amy Fleming, tells us that she can often taste "chopping-board" or even "washing-up liquid" in food.

Add to that the fact that certain textures can also cause discomfort and you find that some children will only eat smooth foods like mashed potatoes or ice-cream, or will only tolerate putting certain things in their mouths – whether that be a particular mug/spoon or a favored toothbrush. Hardly surprising then that some people (both with and without ASD) become such fussy eaters.

Perhaps though your child loves food and delights in eating things that have strong flavors? Or eats anything and everything whether edible or not – so that nothing is safe whether it be soil, grass or even play-dough (a condition known as pica which may sometimes be related to a lack of vitamins and minerals.)

This is the child who is “hypo” (under-sensitive) so that tastes, smells and flavors never seem very strong to him and he is unable to detect or differentiate between different tasting substances. Unfortunately, this child often puts himself at risk because he eats indiscriminately.

Finally, there is the child who falls into the category of “white noise” as identified by the late Dr Delacato. The child he believed had a constant taste in his mouth; who sucked his tongue or chewed the inside of his mouth. One who even regurgitated food so that he could re-chew, re-taste and re-swallow it. A child who was generally apathetic about food, allowing others to feed him but rarely doing so himself.

He also found that such children often also have thickened tongues due to the constant sucking.

Top Tips

General points:

☐ Be relaxed and don’t make meals into a battleground. Look at his food intake over a week rather than on a daily basis.
☐ Offer favorite foods alongside a small portion of a new food and just see what happens – but don’t push it.
☐ If texture is a problem try pureeing food.
☐ If using supplements:
☐ Mix tiny amounts of supplements with a food he likes and gradually increase the amount.
☐ Make ice pops with liquid vitamins.
☐ Use calcium and magnesium in cooking and baking.

For the hyper child

- ☐ Use bland foods.
- ☐ Give small portions.
- ☐ Avoid carbonated drinks.
- ☐ Mix tiny amounts of any new food/drink into something you know he likes and then increase the amount of the new food very slowly.

For the hypo child you need to ensure that:

- ☐ He cannot access certain areas like the kitchen/bathroom by himself.
- ☐ All cleaning materials, mouthwash, medicines etc. are kept under lock and key.
- ☐ He eats a balanced diet.

The child who has a constant taste in his mouth:

- ☐ Should be discouraged from regurgitation.
- ☐ Will benefit from “exercising” his tongue – see www.autismdecoded.com

OTHER RESOURCES:
http://www.autism.org.uk/restricteddiet
http://theeatinggame.ca/ – The Eating Game

NOTES

Sensory Differences. The Consequences Are No Fun!

You have seen how badly the various sensory differences can affect the child; transforming the way he relates to others and to the world around him. But unfortunately the consequences of those problems are often overlooked despite the fact that, in my experience, they are very important indeed.

So before we continue to look at the many other differences that might affect your child perhaps we should pause to consider the ramifications of those sensory differences.

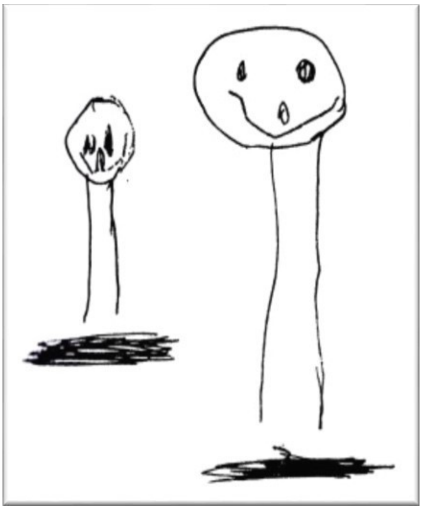
Earlier we looked at the effects the sensory differences might have if the child grew up with them. What though of children who seem to be developing normally until (for whatever reason) that development stalls, stops and then goes "into reverse" – something that often occurs between the ages of 12 to 18 months old?

Such children lose previously acquired skills and, if their senses also "unravel" (as they seem to), they will no longer see, hear or even feel as they used to. Sometimes even their sense of balance and proprioception (an essential part of the body's ability to move) disintegrate too.

In effect their world suddenly shifts shape. Is no longer predictable. Instead the jumbled information his brain now receives is disorientating and confusing; leaving him in a nightmare world.

In medieval times, the ordinary folk, most of whom were illiterate, explained such seemingly inexplicable events through stories of changelings that were woven into folk lore: all having a similar theme – of a young child being stolen by fairies or piskies and replaced by a stranger.

And yet looked at from another angle the picture alters completely. No longer is the child stolen. Instead (either suddenly or more gradually) it is the child himself whose finds that his whole family has been transformed so that they are no longer the people he knew. The child who finds that the world around him – and everything that formerly gave him comfort – hurts. Hardly surprising then if he withdraws into himself or if his reactions become strange and unpredictable.



My second book *A Positive Approach to Autism* (2000) told the true and tragic story of two young brothers who both developed autism during their second year. Whilst both now also have bowel problems (something we'll explore later in this series) their mother described the way in which their former abilities degenerated and the sensory problems gradually gained prominence.

Thus the eldest child became progressively hypersensitive to touch and sound and also developed double vision as you can see from the drawing he did of his Mom – seeing two of her – one large and near to him and the another smaller and further away.

Nowadays his eyes trouble him greatly, being very dry, and, as the picture indicates, each eye works independently at times. Can you imagine just how horrendous living with such distorted images must be?

Meanwhile the younger went from showing no sign of clumsiness to being identified as a clumsy child in a relatively short period of time. Sadly, he also lost the ability to see colors and, worst of all, gradually "lost touch with his body." Thus his spontaneous facial expressions and movements gradually became labored and exaggerated – and (to his mother's distress) now attract attention and laughter.

Small wonder then that he has a number of behavioral issues, for he has suddenly found himself wrenched out of a normal childhood and thrust into a strange and incomprehensible world where his perceptual experiences no longer match previously known realities. How is he to understand a world turned into chaos? How indeed would we?

Perhaps (fortunately) the nearest most of us will experiencing anything similar is being lost in a thick fog which baffles and disorientates us. Time and distance are distorted. You still see, but what you see bears no relation to reality; you still hear, but can no longer discern which sounds are close and which are distant, for everything appears unnatural and distorted.

The consequences? Terror. Fear. Anxiety. And the way the child copes with those feelings is through withdrawal, a dislike of change and obsessive or compulsive behaviors.

NOTES

Anxiety – The Shapes of Fear

Does your child withdraw into his own world at times? Or get upset by changes in his routine or environment? Is he reluctant to try anything new? Have routines that simply "have to be done" often in a specific order? Or is she a "collector" – filling her pockets, her room or even the whole house with the things she is interested in?

Not everyone shares my view but I believe that such universal reactions to fear and anxiety are part and parcel of the Autism Spectrum and are indicative of the great stress that such children live with on a daily basis: signs which, because they tend to become an integral part of the child's life, should perhaps be termed *"autisms."*

Let's explore each one in more detail.

- *Withdrawal* is the child's way of protecting himself from a confusing and terrifying world. While some children will physically remove themselves from a situation, others will simply *"disappear on the spot"* – retreating into their own world and ignoring or excluding anything that might trigger their anxiety. At such times they often appear deaf and blind to the things going on around them and that in turn will severely limit their social interaction, the development of social skills and even speech.
- *Routine* is extremely important as it provides some constants in a perplexing and confusing world. Reactions to change are very individual with one child becoming distressed by apparently small things like an item that is out of a place whilst ignoring larger changes and another doing exactly the reverse.

- *Curiosity.* Such children generally find new activities/places frightening and that can inhibit their natural instinct to explore and play. Children who do show curiosity often tend to direct it towards objects rather than people – perhaps because people seem more unpredictable.

- *Obsessions and compulsions.* Such automatic behaviors begin as a way to help the child shut the world out, for focusing attention on them helps keep anxiety at bay, but eventually those behaviors tend to "take over."

- Obsessive and compulsive behaviors may include:

    - Repetitive behaviors like spinning things, flicking a bit of string repetitively or lining toys up in rows.
    - Doing specific actions a particular number of times (and even "having" to begin again if the process is interrupted before it is complete).
    - The compulsive collecting of particular toys/CD's etc.
    - A preoccupation with a particular subject that he talks about repetitively.

NB Some children also use "self-stimulatory behavior" (stimming) so that they may rock back and forth to soothe and calm themselves. Even so it is likely that some stimming is actually related directly to the sensory differences.

Physical effects:

- Interfere with the digestive process – which can cause severe stomach pains during or after meals.
- Weaken the immune system.
- Cause vitamin and mineral deficiencies (which is why mega-doses of such things can sometimes be of benefit).

Anxiety can also:

- Interfere with short-term memory (although long-term memory may be brilliant).
- Interfere with the ability to concentrate and learn.

- Cause panic attacks. Those can result in any of the following reactions:
- Leave the child “frozen with fear” so that he is totally unable to do anything (even something nice like eating a cake).
- Trigger a “fight or flight” reaction so that he may suddenly “attack” himself or another person or run away from a situation.

NB Panic attacks often result from acute anxiety but can also be caused by sensory or emotional overload or simply by too much direct attention (another area to explore).

Top Tips

- Alleviating the sensory differences will reduce the child’s anxiety.
- Introduce new activities gradually and with care, even if you consider them pleasurable yourself.
- Try to ignore stereotyped behaviors unless they are anti-social. If it is very difficult to cope with (e.g. spitting), establish clear guidelines and try to limit it to a certain place.
- Try to keep the number of special objects acquired within reasonable limits.
- DO NOT punish him by taking those “special objects” away as that will only increase his stress and could lead to unnecessary tantrums.

NOTES

Overload – One Thing at a Time

Does your child peer at things out of the corner of his eye or take quick short glances? Is he slow to respond to your questions? Or find it hard to walk and talk at the same time?

This seems to happen because, in contrast to most people, who automatically process information from several senses simultaneously and then react to it, the child can generally only cope with one bit of information at a time – "mono-processing." Thus he often uses peripheral vision rather than looking directly at a person or object because that limits the amount of stimulation he receives.

While hearing differences provide one reason for his slow response to questions, mono-processing is another, for it means that there is often a time lag between the question and his ability to take it in and then reply. And that delay can sometimes make his answer apparently meaningless as the conversation has long since moved on.

So why would he be unable to walk and talk at the same time? Sadly, some of the actions that most of us do quite automatically actually necessitate conscious thought on the part of the child with ASD.

And that makes everyday life exceptionally difficult. Just imagine if you really had to concentrate in order to be able to walk. Or stop walking simply so that you could speak. But mono-processing is only part of answer for other factors come into play too as you'll see shortly.

Even so, despite the difficulty he has in processing information, it seems as if the majority of such children do take in everything that is going on around them – even when they appear to be in a world of their own.

And yet they are generally unable to "process" or assimilate that information fully until they are alone or in a quiet place: which is why such children often do much better in a relatively quiet classroom.

Perhaps that explains how such children sometimes surprise their parents or teachers by displaying abilities that others did not know they had – like the two I know who both taught themselves to read without anyone realizing.

So what happens when those coping mechanisms are not enough and the child finds himself overwhelmed by everything going on around him – adding to the anxieties he already has? Once again we find that overload initiates a range of automatic reactions similar to those already discussed.

The result? This is the child who suddenly "explodes" with blind panic. Or withdraws abruptly, or becomes more obsessive or compulsive. The child who freezes. Sometimes though the reaction is even more severe so that he becomes extremely lethargic. Or even falls asleep without warning as his brain "shuts down" in order to protect him: something that can be mistaken for epilepsy.

Such reactions are echoed in the accounts of people who were unfortunate enough to find themselves living under great stress. While examples span the world for now I'll just focus on two people, both of whom were held hostage in Lebanon towards the end of the last century.

Thus in his book *An Evil Cradling* author Brian Keenan described an incident in which he raged in a blind panic as he was transported in the boot of a car whilst in his book *Taken on Trust* his fellow prisoner Terry Waite talked of a period during his captivity when he felt a compulsive need to tell himself a story and simply could not stop until he reached the end.

Perhaps you think that the anxiety felt by people with ASD is not comparable to the intensity of the fear the hostages faced? Sad to say I'm afraid it often is.

A study by researchers at Brigham Young University confirmed that anxiety is a major problem in autism and is frequently debilitating (and sometimes overlooked). They also identified it as one of the most disabling factors in older children and adults. Given all the stresses involved such findings hardly seem surprising do they?

Top Tips

- Avoid overload wherever possible.
- Use calming techniques – music, walking or trampolining etc.

More ideas can be found at:

https://www.understood.org/en/friends-feelings/managing-feelings/fear/8-self-soothing-techniques-for-your-young-child

http://connectability.ca/2010/09/23/calming-strategies-to-use-with-children/

http://www.myaspergerschild.com/2008/05/calming-techniques-that-work-with.html

https://www.speechandlanguagekids.com/calming-children-self-calming-strategies/

NOTES

Exposure Anxiety. Don't look at me!

Does your child get you to turn the door handle or pick his toys up? Do you sometimes catch him doing things or perhaps even hear him talking or singing to himself when he thinks he's alone? Does he avoid using personal pronouns? Or is his speech nonexistent or limited to a few "*safe*" words or phrases?

If so it is possible that he suffers from Exposure Anxiety (EA); a condition which was identified by Donna Williams in her book *Exposure Anxiety—The Invisible Cage.* Although the roots of this problem are complex it is similar but far more severe than social anxiety disorder.

EA can be quite crippling as it causes the person to feel acutely self-conscious and leads to a persistent and overwhelming fear of interaction.

And that makes any attention from other people feel potentially threatening so that the child feels "*exposed*" each time someone looks at him, talks to him or even compliments him.

Most children cope with this by attempting to "*block out*" the triggers. That can lead to some strange reactions as he may ignore the people he likes most or respond to direct praise by losing interest or disowning (or even destroying) his achievements.

The concept of exposure anxiety challenges many common assumptions such as:

- The child is rejecting – for although his actions may indicate that, they do not necessarily relate to his real feelings.
- Stereotyped behaviors should be discouraged – which misses the fact that such behaviors can often be positive – acting as a gateway to learning, a reward, or even a pressure valve which helps the child unwind when he is particularly stressed.
- Bad behavior should be ignored and good behavior should be praised for, while this works for many children, it is counter-productive for children who cannot cope with direct attention.

So how can you help? The best way is to approach things INDIRECTLY so that you avoid triggering the child's anxiety. Some of the following ideas seem a little strange to start with but even so they can prove extremely effective with some children:

Top tips

- Indirect communication
  - There are times when he wants to do something, but is unable to ask. If so, try asking him to do things for another person. Thus if you think he needs the toilet, suggest he takes a sibling there, as once there he may use the toilet himself.
  - If you wish to discuss a particular situation, try talking about it quietly to yourself when you know he can hear. Alternatively, take advantage of his super-sensitive hearing by talking to someone else about it or by talking to a non-existent person on the phone.
  - If mealtimes are difficult use a similar approach, suggesting (to someone else) that he should eat separately until he can cope. (If he then joins you at the table, don't comment – and don't expect it to happen every time).

- Don't praise or comment on his achievements directly as he may abandon or destroy them. If you want to reward him, comment indirectly, praising the items he used rather than him, for example, "those crayons drew that picture well", or alternatively use a star/sticker system which focuses on the achievement rather than on him.
- If he gets you to do things for him start by doing things for him and then remove your support gradually so that he has to do something himself to complete the action like fetching the biscuit tin for him but only partially opening the lid before you go to do something else.
- Swap roles, for example, when painting or playing an instrument so

that you use his hand to make a picture in the sand, bang a drum, etc.

- Model things by using them while he is in the room – but don't show him how to use them directly as he might reject them altogether.
- Introduce new toys or equipment by leaving them in his room or around the house for him to find but do remember to ignore him if/when he begins to show an interest or use them.

NOTES

The Sixth Sense – Steady On!

Does your child move awkwardly and clumsily? Does he find it hard to pick things up? Or send food flying when he eats? Do the family pets avoid him? Does he slam doors and enjoy games in which he can push, pull or drag things around?

Such problems are linked to difficulties with proprioception (body awareness): sometimes called the sixth sense. This sense is so automatic that we are barely conscious of it and yet it is vital to our well-being for it makes us feel safe and secure in our movements and actions.

Body sense enables us to orientate ourselves in space. It lets us know where our arms and legs begin and end and where they are in relation to one another, allowing us to move without crashing into the things around us.

It also helps us to know whether our bodies are moving or sitting still so that we can move around without having to look at our feet all the time and sit upright without keeling over.

This proprioceptive system also helps us judge how much force is needed to manipulate objects. Without it even the simplest tasks can be problematic and make the child seem like that proverbial bull in a china shop because he is so clumsy and uncoordinated.

This is the child who complains that his glass of milk is really too heavy and cannot pick it up. Or alternatively picks it up so forcefully that it flies across the room because it was lighter than he expected. The child whose food flies off in all directions as he eats. Whose writing is either so light that it is almost invisible or is extremely messy and full of marks that tear holes in the page. The child who unintentionally hurts the family pet because he is too forceful when he tries to stroke or play with it.

How does this fit with ASD?

In her book *Twirling Naked in the Streets and No One Noticed; Growing Up with Undiagnosed Autism*, Jeannie Davide-Rivera suggests this is a major factor for some children. As she writes:

> *Children and adults with autism often have difficulty with proprioception and very well may just be the thing that goes bump in the night…and the day, and at work, and in the streets. Poor proprioception may likely be responsible for those many bruises, skinned knees, and torn stockings that plague our days.*

Body sense is involved in coordinating the muscles in the mouth too, and is vital to swallowing, eating and the ability to speak clearly: hence another reason for the speech difficulties that affect some children.

Could body sense also provide the answer to the telling question asked by Tito Rajarshi Mukhopadhyay (diagnosed as severely autistic) in the title of his book *How Can I Talk If My Lips Don't Move? Inside My Autistic Mind?* It certainly seems to be a possibility. Such difficulties are very frustrating for him. They will also make him feel very insecure, so that he is often afraid of trying new things and lacks self-confidence and self-esteem.

Quick Checklist

- ☐ not reaching motor milestones on schedule
- ☐ continuing to walk on tiptoes (after the age of 2)
- ☐ poor balance – often seems on the verge of falling
- ☐ seems to have weak muscles and tires easily
- ☐ movements are not smooth and coordinated – seems stiff or floppy
- ☐ poor posture; slumps when sitting or uses feet for support
- ☐ looks at the ground when walking
- ☐ frequently spills, breaks or bangs things
- ☐ looks at the ground when walking
- ☐ bites/sucks fingers or chews cuffs, pencils, toys
- ☐ accident-prone; falls or bangs parts of body

- holds crayons/pencils too tight or too loose
- enjoys and seeks activities such as jumping, wrestling etc.
- enjoys being held tightly (or the opposite – avoidance of hugs or touch)

Top Tips

Proprioceptive activities are many and various and can include:

- Activities like trampolining, climbing, digging, pulling heavy toys along, bear hugs etc.
- Deep pressure massage
- Chew toys, chewy/crunchy foods
- Stress balls, balance boards, weighted vests/blankets

For more information, see:
http://www.ot-mom-learning-activities.com/sensory-integration-activities.html
https://sites.google.com/site/smallschoolot/information-for-parents/more-proprioceptive-activities http://www.spdaustralia.com.au/
http://www.autismdecoded.com/Learning-Breakthrough™.php

For speech:
http://englishagenda.britishcouncil.org/seminars/proprioception-learning-new-sounds-words-and-connected-speech

NOTES

The Seventh Sense. Spinning and Swinging

Is your child afraid of heights? Does he hate escalators? Get sick every time he travels? Or hate swings or any game that puts him off-balance? Or is he totally the opposite? A child who never gets giddy or travel sick? Who really enjoys the rides at the amusement park? Who's constantly jumping about or hopping around? One who loves swinging as high as he can?

If so it is likely that his vestibular system is not functioning as it should. This complex system is based in the inner ear and provides the brain with information about movement and balance, as well as space and gravity. That information combines with other sensory input – from the eyes, muscles and joints – thereby enabling us to balance and move with ease.

Anyone with a vestibular dysfunction will have difficulty integrating special awareness, gravity, balance, and movement.

And that will show in a number of different ways. Thus one child may be over-sensitive to movement and will therefore tend to avoid situations whilst others will be under-sensitive to movement, and some will seem to be hyper at times and hypo at others.

Children who are hypersensitive in this area may:

- Fear crawling / walking.
- Wave their arms out to the side or hold them close to the body – to help maintain balance.
- Dislike physical exercise.
  Be uncoordinated, clumsy or awkward – often bumping into things
- Easily lose their balance or stumble/fall.

- Dislike unstable surfaces and have difficulty learning how navigate stairs or to go up and down sloping surfaces.
- May rock or swing gently – as this can help calm his overly-excited vestibular system.

In contrast children who are hyposensitive will generally have an increased need for movement and crave lots of vigorous activity. Thus they will:

- Seek vigorous activity – like twirling, spinning or swinging.
- Like jumping up and down.
- Have no fear of heights at all.
- Make exaggerated rocking movements – swaying from side to side – or forwards and backwards.
- Appear hyperactive – unable to sit still and constantly on the go.

Because the vestibular system is located in the ears sudden loud sounds can cause or increase the symptoms of vertigo, dizziness, or imbalance – and some people may even experience a sensation of fullness in the ears.

Other indications could include:

- Staring at one point fixedly.
- Sticking the tongue out or making facial grimaces.
- Anxiety, panic and social isolation.
- Sensitivity to pressure/temperature changes and even the wind.
- Slurred speech.
- Pain, pressure, or other symptoms with certain dietary changes.

Because balance, movement and learning all go together life can be very hard for some children leaving them lagging behind their peers: and often diminishing their self-confidence and self-esteem.

Top Tips

- Exercises to help strengthen and normalize the vestibular system can be great fun but go at his pace – never force him to do more than he wants.
- Swinging.

- Spinning and twirling games using a balance ball, wobble board or even a rotating chair.
- Take advantage of your nearest park and encourage the child to try different rides.
- Make an obstacle course where he can jump, hop etc.
- Help him learn to ride a bike – using stabilizers where necessary.

NB Some of these exercises can make the hyper-child feel giddy so begin by making them brief. Try to avoid over-stimulating him.

In the classroom

- Have built in rest times
- Let him use a sloped surface for writing.
- Let the child sit as they need to – children tend to work out best to stabilize themselves which may not necessarily mean sitting upright.
- Remember that he may be able to write or sit up but not both together.
- If he needs to support his head on his arm do let him.

Talk to an Occupational Therapist if possible as they may be able to advise you on exercise and will also have access to equipment such as low, wide swings with wide bases that make swinging a low risk activity.

References: http://vestibular.org/understanding-vestibular disorder/symptoms
http://milesandmarley.blogspot.co.uk/2013/02/vestibular-dysfunction-and-sensory.html

NOTES

Digestive problems – Food for Thought

Now we've explored some of many sensory and other symptoms commonly found in people on the autism spectrum we need to turn our attention to the physical problems that also affect many of them, regardless of age.

Ongoing (and sometimes disputed) research indicates that many children with ASD suffer from one or more of a range of dietary/digestive/gastrointestinal problems which can affect not only the brain but also mood and behavior. Even so it is important to note that if the underlying problems can be identified and treated correctly ASD-related behaviors often improve too.

So let me begin by asking whether your child ever gets agitated prior to or shortly after meals? Or sometimes gets so hot and sweaty that he suddenly throws all his clothes off? Does he crave sweet or junk food – only to roar around the house after he has stuffed himself full?

If so, he may be suffering from "Reactive" hypoglycemia – a drop in blood sugar levels (not associated with diabetes), a condition that can often go unnoticed in people with ASD. This can affect children who are hungry (as they often are after returning from school), or those who have had an intake of sugar, junk food or stimulants such as caffeine.

That drop in blood sugar can give rise to a whole variety of symptoms which includes weakness, shakiness, hot and cold sweats, a loss of concentration, anxiety, irritability and confusion as well as migraines/headaches; blurred vision, vertigo and, in severe cases, fainting – or even seizures.

Often the first sign is that hot sweat – something that can lead to a bizarre hazard. Author Teresa McLean describes this clearly in her book *Metal Jam* when she tells us about a time when she was working as a teacher, and having a sudden hypo attack (caused in her case by diabetes) she began undressing in front of her class. Understandable but oh so embarrassing.

That drop in blood sugar also produces an excessive amount of adrenalin: and that adrenalin rush gives rise to its own problems for, being part of the fight or flight mechanism, it gives a sudden burst of energy and increased strength, heightens the senses and even reduces the feeling of pain. Perhaps low blood sugar and high adrenalin explain the boy who, as soon as he got home from school, ran away, undressing as he went.

Top Tips

- Eat small meals and snacks throughout the day, no more than three hours apart so:
  - Give him a snack when he gets home from school.
  - Provide snacks that he can have at school – and let the school know the reason why.
- Eat a well-balanced diet, using foods that have a low glycemic index (GI) – lean and nonmeat sources of protein, and high-fiber foods, including whole grains, fruit and vegetables.
- Avoid foods such as white bread, processed breakfast cereals, cakes and biscuits.
- Avoid/limit sugary foods, especially on an empty stomach.

Useful resources:
http://www.allaboutyou.com/health/diet/seven-day-gi-meal-plan-23453
http://www.totallynourish.com/recipes/en

Hypoglycemia is only one of many possible problems so now to look at some of the other common problems some of which are interrelated. That includes:

- Food intolerances – especially to casein (milk) and/or gluten (wheat)

– and other foods like chocolate or oranges. Unlike food allergies the effects of such intolerances tend to be behavioral – so that the person may become hyperactive or disruptive – often within a few hours of eating.

- Leaky gut – where the wall of the gut is damaged and lets food particles through. This can cause abdominal pain, heartburn, insomnia, bloating, anxiety, gluten intolerance, malnutrition, muscle cramps and pains, and food allergies.

- Candida (thrush), a fungal infection which can contribute to a leaky gut.

- Irritable bowel syndrome (IBS) – the symptoms of this can be quite variable and can include intermittent abdominal pain, bloating, wind or bouts of diarrhea and/or constipation. Other symptoms may include fatigue, nausea, headache, poor appetite, backache, muscle pains or heartburn after eating.

Reference: Metal Jam: The Story of a Diabetic – Teresa McLean

NOTES

Gastrointestinal (GI) Disorders – Gut Feelings.

Does your child suffer from stomach aches? Or have bouts of diarrhea or constipation? Is his stomach bloated at times? Do his bowel movements contain undigested food particles? Or does he arch his back, press his stomach against things or grit his teeth? Or scream or rock?

If so it is possible that he has any one of the most common medical conditions associated with autism, in both children and adults, that range from chronic constipation or diarrhea to irritable or inflammatory bowel conditions.

These problems affect although most of the research area has focused on children who, according to the Centers for Disease Control and Prevention (CDC), are over 3.5 times more likely to suffer from chronic diarrhea or constipation than other children. Meanwhile other research shows that the pain and discomfort caused by GI symptoms is associated with a deterioration in behavior and may even trigger regression – particularly in those who are nonverbal.

Looking back into the history of ASD we find that chronic constipation and diarrhea are age-old problems. Thus Dr William Dickinson who worked at Great Ormond Street Hospital for Children in England, from 1869 to 1874 found such problems in several of his patients – as he recorded.

One patient was Ralph (whose behaviors were indicative of ASD) and who was suffering from constipation when admitted at the age of 2½. He had developed severe feeding and gastrointestinal problems and had had multiple bouts of diarrhea which began when he was about 8 months old, the first attack lasting 5 weeks!

Then there was Ida, who had apparently been developing quite normally until infantile epilepsy struck when she was just 3 months old. She then began to fit on a daily basis, having anywhere from one or two to as many as 30 seizures, that lasted from just a minute to a whole day.

When finally admitted to hospital at the age of 2¾ she was found to be "a well-nourished child . . . with a fresh color", but even so, she suffered from severe constipation, which staff thought might be causing her nocturnal screaming fits and disturbed sleep.

On treating both the seizures and the constipation they saw a remarkable change for, as the ward staff reported, after four bowel movements her screaming and rocking quieted noticeably, her sleep improved and she became more engaged with the world around her, appearing to notice things more than before.

At one point her symptoms worsened dramatically as did her acute constipation and she began screaming and rocking again. Eventually though the improvements returned and things stabilized, although as authors Mitzi Waltz and Paul Shattock OBE point out in their article *Autistic Disorder in Nineteenth-century London* whilst medication for the seizures made a difference, it was only when her constipation was controlled that her improvement was maintained.

Next to Dr Grabham, Superintendent of The Royal Earlswood Hospital in the UK, then a center of excellence. In January 1875 he published his observations in the British Medical Journal in which he noted that many of the children he worked with (who would fit today's criteria for ASD) had digestive problems. As he wrote:

> *Assimilation is very imperfectly performed; the food, if not very digestible, sometimes passing most unchanged. diarrhea in some is the rule rather than the exception.*

We'll return to look at irritable and inflammatory bowel conditions in more depth next week. Meanwhile always seek medical advice if the child has frequent bouts of diarrhea (once a day or more) or is chronically constipated. These are serious issues and the causes need to be identified. It is also important to note that runny diarrhea can sometimes be indicative of severe constipation and impaction (a blockage of faces).

Top Tips

- If he has diarrhea make sure he drinks enough water.
- Use a good probiotic every day.
- Magnesium is natural laxative and is something that is often depleted (as are many vitamins and minerals) in people with autism. Even so it is pretty powerful so always begin with a relatively low dose – see http://ibs.about.com/od/constipation/a/magnesium.htm

More useful information can be found at: http://www.tacanow.org/family-resources/the-poop-page/

If the problems are associated with Irritable Bowel Syndrome the child might benefit from the FODMAP diet: http://www.ibsdiets.org/fodmap-diet/fodmap-food-list

NOTES

More Gut Feelings

You already know there are several different GI problems that commonly affect people with ASD so perhaps we should explore some of the most common ones in more detail in case your child has any of them.

Does your baby cry inconsolably, refuse the bottle or breast and then cry for food again only to pull away when it is given? Or belch, burp or vomit when eating? Or wake in the night with tummy pains? Or suddenly become very irritable or aggressive for no apparent cause?

Although such symptoms may have been dismissed as colic in the past it is now believed that at least some cases of unexplained, inconsolable crying may actually be due to gastroesophageal reflux (GER).

This often affects babies (most of whom outgrow it by the time they are 12 months old) but is also relatively common amongst toddlers and children with ASD.

GER occurs when the muscle at the entrance to the stomach fails to keep the stomach contents in the stomach – causing the excruciating pain that adults call heartburn but it can also cause other symptoms like coughing or wheezing as well as failure to gain adequate weight and bad breath.

If you think that your child is suffering in this way do consult your doctor or pediatrician as soon as you can.

Ideas to help:

If the infant is still nursing:

- Milk acts as a natural antacid so the baby might want to eat frequently. That can cause problems as reflux can worsen if he is overfull.

- Other babies quickly learn that eating causes pain and so they refuse to nurse.
- To help overcome this try: varying positions, feeding while the baby sleep, or walking while nursing.

See: *Breastfeeding the Baby with Gastroesophageal Reflux* by Laura Barmby for more details.

General tips

- Warm baths and infant massage may help to calm a distraught baby or toddler.
- Give smaller meals more frequently so that the child doesn't get overfull.
- Avoid food for at least two or three hours before lying down.
- Avoid tight clothing around the waist.
- Diet plays a major part in reflux so try using a diet aimed at people with GERD, many of which can be found on the internet.

Now though to turn our attention to two interlinked conditions. First Candida albicans (also known as thrush), a fungal infection. This is known to affect many people with autism.

Risk factors:

- A history of baby thrush, diaper rash or cradle cap.
- Skin rashes.
- A high-sugar diet – as that can weaken the immune system.
- Oral thrush (a white film in mouth or on lips or tongue)
- Colicky for more than 3 months.
- Symptoms worse on damp days.
- Recurrent ear problems.

- The repeated use of antibiotics which kill off all the bacteria (both the bad and the good) that we need to keep the digestive system functioning correctly.
- Continuing constipation.
- Stress.

For a free dietary guide to beating candid see:
http://www.thecandidadiet.com

Leaky Gut – a condition in which the wall of the gut is more permeable than it should be. This causes toxins get into the body where they wreak havoc and is implicated in a range of symptoms which include:

- Abdominal pain, bloating, diarrhea or irritable bowel syndrome - IBS.
- Seasonal allergies or asthma.
- Hormonal imbalances.
- Auto immune diseases such as celiac disease.
- Brain fog.
- Skin rashes.
- Anxiety.
- Malnutrition
- Muscle cramps and pains.

It can be triggered by a number of factors including candida, various toxins, stress, dysbiosis (an imbalance between beneficial and harmful species of bacteria in your gut) as well as some foods like gluten, dairy and sugar.

How to help:

- Avoid gut-irritating foods by changing your diet – see The Myers elimination diet.
- Use a good probiotic to support the good bacteria in the gut.
- Eat foods that will reduce inflammation and help the gut heal. This includes Omega-3 fatty acids found in large quantities in wild-caught

fish, pastured/free-range eggs, and free range animals – although you could use a good quality fish oil supplement instead.

- Also see *4 Steps to Heal Leaky Gut*.

NOTES

Thinking. Just a Thought!

Does your child seem other-worldly? Is he anxious, sad or happy whenever you are? Does he speak in a very idiosyncratic way – as if his mother tongue is a foreign language? Or does he disconcert people because he seems to have a real insight into them?

If so that may be related to his stage of thought for, like every other aspect of our lives, thought too has its own developmental path.

In early infancy the baby lives in a world of sensing while at the next pre-verbal stage the infant will think in pictures, until he finally learns to interpret the world in words.

As Donna Williams tells us in her book *Autism and Sensing: The Unlost Instinct,* at that early "preconscious" stage the baby's world is dominated by pattern, theme and feel: in which things are sensed and felt both through body and movement – but never interpreted.

So when autism develops at an early stage some children with ASD get "stuck" in that sensing stage. Some, like Donna, retain the gift of sensing, even after they have gradually moved on to thinking in words.

However, many of those who do "move on" actually lose that sensing ability once they learn to interpret words in a different way – like Nadia, who had autism and severe language delay.

A gifted artist she began drawing all over the walls when she just 3 – drawing eloquent and remarkable pictures of horses, horsemen and more, only to lose her artistic ability as she learnt to speak.

Maybe though your child's problems are different. Does your child find it hard to follow conversations? Or have difficulty responding when spoken to? Or do his gifts lie in the area of art, design or computing?

If so, like many people with dyslexia – and some, others with ASD – he may think in pictures. Much of the research in this area was initiated by Ron Davis who had a whole range of problems throughout his childhood, the most daunting being his inability to read.

Despite that he made a fortune in engineering and, after finally managing to teach himself to read and write, he founded the Davis Dyslexia Association International (DDAI) to help others.

Thinking in pictures is a major hindrance when people learn to read because the person builds up a picture in his mind, adding to it as more concepts arise. It is far faster than thinking in words and an advantage in the arts and computing but it puts the child at a real disadvantage when he learns to read.

That is because while it is easy to visualize nouns, verbs and some other words, other words (particularly abstract concepts such as pronouns and adverbs) like "I, you, it, with, if" or "and" are much harder to visualize.

Thus the sentence "His house is big and it has a chimney pot" would seem to read "… house… big … … … chimney pot". Confusing! Does the word big relate to the house or simply the chimney pot?

One of the most well-known people with Asperger's is Dr Temple Grandin. Despite having Asperger's syndrome, she gained a doctorate in animal sciences and now designs equipment for handling cattle that is used across the world. And, as her book *Thinking in Pictures* shows, thinking in that way has been a great help in conceiving and developing her designs.

It is probable that visual thinking underlies some of the cognitive problems and speech difficulties that such children have.

If you cannot easily conceive the meaning of such words, how can you possibly understand sentences easily? Or respond easily and fluently, for there will always be a time-lapse as you "translate" the words into an informative picture and then "translate" back into the words you need. No wonder such children find it hard to "keep up" with the conversation.

A final thought. Could those different ways of thinking help to account for the differences between people with autism and those with Asperger's syndrome? Yes, I know it's been knocked out of the DSM-5 but I happen to think it probably does. What's your view?

References:

Nadia – Lorna Selfe
The Gift of Dyslexia – Ron Davis

NOTES

Thinking. Second Thoughts.

Is your child's speech appropriate even though he takes some comments literally? Are you concerned that although his understanding is good he still finds it hard to understand abstract concepts, sarcasm or jokes that have double meanings? Or gets confused when people say things like "that film was a good watch" or "the game is a must see"?

If so it may be that the onset of autism has halted, slowed (or even reversed) the usual developmental process: something that has a whole range of problems that can leave his level of understanding out of kilter with his intelligence.

Not only do such things interfere with his ability to socialize, communicate and the child's innate need to explore and play but, in turn, they affect his cognitive skills (like attention, memory and the ability to learn new things easily).

Babies are attuned to their moms" voice before they are born so, although they don't know the meaning of the words they hear, they can recognize her voice. By about six months old they will have begun to understand simple words but after the 14th month word recognition jumps dramatically and so by the time they are about 18 months old most babies can understand around 50 words and follow simple instructions like, "pick up the building blocks."

At that stage they tend to use less words than they know so they often add gestures to help show you what they want. But their understanding continues to develop and by the age of two and a half years old, they can use around 200 words and even make short sentences.

Even so their understanding is still limited so that they take things literally: something that is especially noticeable in three- and four-year-olds – and continues until the age of six or seven, giving rise to misunderstandings and comic situations, of which I will quote only two:

The small girl who stopped eating because her mother had told her to *"eat it all up – it will put hairs on your chest."*

The young boy, left in the bath while his mother answered the telephone, who shouted, *"Mummy, hurry up, I'm going rusty."*

Not all such situations are amusing though for taking things literally can often cause confusion and distress, as with the child who had a tantrum when offered "marble" cake.

Such difficulties in understanding and cognition also makes it very hard for the person to engage in "small talk": something that most of us use automatically when we talk to others – whether we know them or not.

Even so "small talk" generally has a predictable repeating pattern – regardless of who is being spoken to – for it comes at the beginning and sometimes the end of a conversation. Author Judy Edow describes it as a sandwich in which the important words are the filling and the bread is the small talk so that just picturing that sandwich reminds her to start and end her important words with small talk.

Top Tips to help with "small talk":

- Use games, role play/play acting, social stories, prompts, puppets etc. to work on "taking turns."
- Let him choose a topic – depending on the age of the person concerned – that could include:
  - school activities
  - weekend activities
  - TV shows
  - the weather (especially in the UK!)
  - compliments
- Give him some useful "scripts" about any of those subjects so that he/she can retrieve and use where appropriate such as:
  - *"Are you looking forward to…………?"*
  - *"Do you like …………….?"*
  - *"Did you go to the ………………. at the weekend?"*
  - *"Did you watch/enjoy ……………… yesterday?"*
- Include scripts that are appropriate to use with friends, school or

work mates and others that can be used with teachers / employers.

- Teach/model the use of prompts like – "Wow! That's interesting.", "No kidding!".
- While people with ASD are often sensitive to others feelings they may have trouble showing it. Once again it will be helpful to model situations and also give them some appropriate phrases that they can use to comfort the other person such as: *"That must hurt"* or *"Can I help?"*

Reference: Judy Edow's blog: http://www.judyendow.com/hidden-curriculum/the-big-deal-about-small-talk

NOTES

TREATMENTS AND THERAPIES

Where Should You Begin?

Do you take your child's autism in your stride, seeing it, simply, as a different way of being: one that is very much part of him? Do you see treatments and therapies as unnecessary; believing that autism is just a different way of learning?

Or are you a *"warrior mom"* who, feeling your child has been poisoned or injured by external factors like vaccinations, has set out to rescue your child from "his" autism: something you see as separate to the child himself?

Do you search the Internet avidly for new ideas? Or simply feel you must try every new thing that comes along?

Sadly, today, once a child has been diagnosed, parents can feel as if they had just landed in a crowded bazaar where they are beset on all sides by people plying their wares, touting a bewildering array of treatments that they say will help the child (and, sometimes, part parents from their money).

Some are certainly real and serviceable although, sadly, others are just plain wacky. Some vie for attention by telling you *"how it will be if only you try this"* whilst the less scrupulous opt for coercion, by using a *"how it will be if you don't try this"* approach. To make matters more complicated the effects can vary widely: so that one child is seemingly cured while another seems to gain only a moderate or minimal benefit from a similar approach.

So if you're looking at treatments/therapies to determine which are worthwhile perhaps I can help you by offering an unbiased view of some of them: assessing the truth behind some of the claims.

My interest in autism began in the late 1960s and led me to spend several years working with people with ASD. I then began to research the subject in the late 1980s, publishing my first book in 1990.

A born sceptic, over the years my ongoing research has led me to investigate a variety of approaches, including some that would be considered alternative. Most importantly I have also experienced the effects of mild sensory differences myself.

So let's begin with something that even those who shy away from treatment cannot ignore: physical problems of any kind. If so you will need to seek professional help, for these can have a real impact on his well-being and also his development.

First epilepsy, which is more prevalent among children with ASD than their peers. This results in seizures or periodic loss of consciousness caused by a disturbance in the electrical activity of the brain.

There are several different types of seizures commonly found in children with autism some of which can be "triggered" by certain situations from lack of sleep to stress, illness or flickering lights. They include:

- Infantile spasms. These usually begin within the first year of life, often between the ages of 3 to 8 months. Spasms often occur several times in a row and such clusters can occur several times per day. These spasms can disappear by the time the child is three or four years old but even so some children will continue to have neurological problems.

- Atonic seizures – ("drop attacks") in which the muscles suddenly relax making the child floppy – something that can be dangerous as he could fall and injure himself.

- Absence epilepsy (also known as petit mal) in which the child becomes unconscious for a short time. He may look blank and stare or flutter his eyelids and will not be able to respond to things happening around him.

- Complex partial seizures leave the child confused. He may make purposeless repetitive movements (called "automatisms") and wander around or behave strangely. He will also be unaware of what is happing or to respond to your voice.

- Generalized tonic-clonic seizures (also known as grand mal). These are the seizures most people think of as epilepsy as the child becomes unconscious and then begins to convulse (jerking and shaking as their muscles relax and tighten rhythmically).

Top Tip

Record the times/dates and lengths of seizures plus their effects and other relevant information like illness or the situation, as that will help you avoid any triggers and could help the child's doctor too.

See www.epilepsysociety.org.uk

NOTES

Autism Basics – Tools for Survival

Autism has long been associated with food allergies and intolerances but we'll return to them later in this series, for now I'm going back to basics.

Regardless of just where the child is on the spectrum, most parents share common worries regarding the lack of communication and social abilities. For many parents the most pressing of these concerns speech, which arises from the perfectly natural and almost overwhelming need for the child to call them mommy or daddy and say those all-important words "I love you."

Even parents whose child acquired speech at about the same time as his peers may gradually become aware that their child's speech differs in quality from that of his peers. Such children may variously use words and language that seem too grown-up for their age; do not understand the nuances of speech; bring every conversation around to a topic they are interested in; speak too loudly or too softly.

However my research and personal experience of the effects of relatively mild sensory differences (in my hearing, vision, and sense of touch) have convinced me that the problems mentioned in the criteria are simply the tip of the iceberg.

So what could possibly underlie them? Followers of this series will already know that part of the answer lies with those sensory differences because of their vital importance, both on the child's development and in daily life. For those who missed earlier articles let's have a brief recap.

Initially everything we learn about the people in our world, and the world around us, comes through our senses. But the world of autism is ruled by sensory differences, making such "ordinary" learning impossible.

Walk a mile your child's shoes and you will find that how he experiences a hug is often far removed from your loving feelings as the "*hugger*." That he is aware of smells that you don't even notice. That your face – and those of other – may seem fragmented or even blank. That the text in his books swirls around or even – quite literally – seems to jump off the page. That what you hear, and happily, ignore, actually hurts him. And that means that his life is full of confusion and can be very frightening indeed.

Some people will tell you that the child should be encouraged to adapt to his difficulties. And yet they would not expect a short-sighted child to simply “*adapt*” and see properly without his glasses. Nor a partially deaf child to hear without a hearing aid. So why on earth do they expect the equivalent of people with ASD?

In contrast others believe that the world should adapt to him and to an extent they are correct (see the tips given in previous articles). And yet, while many places are now moving towards being “autism friendly” throughout his life there are always going to be places – like shopping malls, school dining rooms and the like over which neither he nor you have any control. But there is another option. To level the playing field between him and his peers by giving him the tools he needs to survive.

That is part of a twofold process for there are some relatively quick survival “tools” that can be used to help him in the short term plus some longer term solutions as well.

Let’s begin with vision for it provides over 70% of our information about the world around us. One of the simplest quick fixes is the use of tinted lenses as many people with ASD have already found. Although still frowned upon by some professionals, I too have validated them through personal experience and certainly have no hesitation in recommending them.

The right tint can help correct some of the visual anomalies, leading to number of benefits which can include:

- Less stress and anxiety
- Better eye tracking and depth perception

- A reduction in confusion and hyperactivity
- Improvements in the ability to concentrate, learn and remember things
- Improved behavior
- Increased confidence, sociability and communication

A free checklist of the visual differences and list of suppliers is available atwww.autismdecoded.com

References:

Like Color to the Blind Donna Williams
http://www.epilepsysociety.org.uk

NOTES

Autism and Hearing – Another Survival Tool

For some children the visual problems mentioned in my last article are less distressing than the auditory differences, some of which, like hyperacusis (hypersensitivity to some sounds), can cause great distress in many situations.

So this is for you if your child dreads going outside because the birds sing too loudly. If he tries to leave the room when you are vacuuming. If he hates mealtimes because of the jumble of noises – especially the sound of other people eating.

If he blocks his ears even when you can't hear anything. It will also be helpful if your child has problems in developing speech and language. Or doesn't seem to understand when other people talk to him.

I've already given you some tips to help but if you want to eliminate hyperacusis, or help him hear correctly it is worth considering a more permanent solution.

As ever there are a wide range of potential solutions available but the one I favor is Auditory Integration Training (also commonly known as AIT).

There are two reasons for this: firstly, because it only takes 10 days to implement. The secondly is personal, for despite only having relatively mild auditory differences my hyperacusis was quite distressing at times and so, after reading about AIT I went on to train as a practitioner using it successfully both with children with autism – and on myself: something I found changed my life in many ways.

AIT was developed in the 1950s by the late Dr Bérard who, after using it to treat his own impending deafness, went on to use it successfully with a vast number of patients whose common link was that they heard and processed sounds in an unusual way. So while some had hyperacusis, others had a variety of auditory differences and associated problems like speech and language disorders or learning difficulties.

Often referred to as an educational program this non-invasive “listening” program simply consists of a wide variety of music, all of which has been specially modulated. That modulation is the key to “retraining” the ear, normalizing the way in which they hear and also helping the brain to process auditory information correctly.

And here I have to admit to a personal interest. Despite only having relatively mild auditory differences my hyperacusis was quite distressing at times and so, after reading about AIT I went on to train as a practitioner using it successfully both with children with autism – and on myself.

So what effects could you expect. For me it was simply relief from hyperacusis – and a less stressful life but there are a whole range of beneficial effects, although those are obviously dependent on the person’s original difficulties. They may include any (or several) of the following:

☐ reduced hypersensitivity to sound
☐ greater tolerance of loud noises and sounds that previously hurt
☐ reduced stress – feeling calmer and less irritable
☐ increased confidence and self esteem
☐ be less hyperactive – less impulsive and distractible
☐ behave better
☐ have clearer speech/improved articulation
☐ show less obsessive/compulsive behaviors
☐ sleep better
☐ be able to listen, concentrate and learn better than before
☐ have better understanding and be more able to remember things
☐ have less need to withdraw from situations
☐ be more communicative
☐ be more sociable – even wanting to take part in social experiences

While the results above tend to be seen once the program is completed, for some people with autism some changes may be noticeable as soon as midway through the program.

One example was the child who had always grabbed his mother's hand for reassurance when large trucks went past. A child who, by the 7th day into the program, was now peacefully unaware that one had just roared passed him. Another was the man in his twenties who had autism. After being afraid of cats all his life on day 6 of the program he actually went up to one and tried to stroke it.

Even so you need to bear in mind that, for some people with autism, completion of the program provides a new beginning; especially if they have missed out on the usual developmental milestones and/or opportunities for learning in their early years.

If you would like a free checklist of the auditory differences, please go to: www.autismdecoded.com

NOTES

Neuro-Developmental Delay – It's Not All About Money.

If you've been following this series hopefully by now your child should be feeling less stressed and perhaps even has one sense that actually gives accurate information about the world around him.

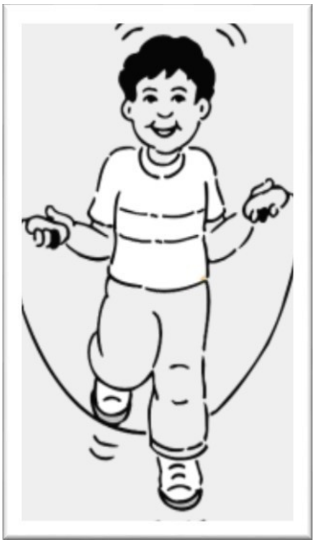
So what should you do next? People who make the mistake of thinking that the problems are behavioral will tend to follow a different path.

However if, like me, you believe that the child's behavior is indicative of his sensory and other problems it is worth using one of the many approaches designed to help children with neuro-developmental delay (NDD).

That is because many of the sensory differences stem from NDD which, interestingly, affects a whole range of people from those who, like myself, have only mild sensory differences, to others whose problems are associated with dyslexia, dyspraxia, Attention Deficit Hyperactivity Disorder, autism or Asperger's syndrome.

There are a number of relatively inexpensive ideas that may help some of which can initially be used at home although you may decide to follow them up with professional advice.

First to a great resource from the BBC (Cbeebies). Called Tree Fu Tom (this can be found on YouTube) or purchased from Amazon, it is aimed at children with movement disorders like dyspraxia but is also designed to assist and enhance the development of all children during those early crucial years.



Aimed at four to six year olds, Tree Fu Tom (voiced by David Tennant amongst others) is set in an enchanted world where movement creates magic. Tom appears to be a normal eight-year-old boy but putting on his magic belt and performing a special sequence of magic action-movements (known as Tree Fu) transforms him into a tiny but mighty magical super-hero.

This is especially good for children who like cartoons as the stories engage boys through a "*cool*" martial-arts feel and also appeal to girls who like elves and fairies.

Developed in collaboration between Dyspraxia Foundation movement specialists Sally Payne and Dr Lynda Foulder-Hughes and series choreographer Nick Kellington the magic moves that children are encouraged to copy are actually therapeutic.

Even better, Tree Fu Tom has his own online section which includes 6 action packed games developed in consultation with a Senior Educational Psychologist plus support in the CBeebies Grown Ups Section.

It may also be useful for older children with autism although, if your child has a degree of Exposure Anxiety, I would suggest that (at least initially) you let him watch it on his own – and just ignore him if he begins to copy the movements as any comment or knowing he is being watched may cause him to abandon watching.

Try it at home:

If your child thinks he is too old for Tree Fu Tom, you might persuade him to try some of the exercises at:

http://www.fernridgepress.com/autism.exercise.phases.html.

Developed the late Svea Gold, a writer and therapist, who worked with children with a variety of difficulties these exercises were initially designed for children with attention problems but should also help those with ASD, although you may have to adapt the language to suit.

If it is not possible to do all of the exercises in the program, choose those which are easily manageable in your own circumstances and if possible, get the child to do them on a daily basis for three or four weeks: by which time some improvement should be visible.

Teenagers might be persuaded to give this program a trial by stressing the expected improvement in athletics, as that can often seem more important to the child than academic achievement. The trial period should be enough time to bring about some improvements which may encourage them to continue with it.

Other useful resources that run similar programs:

Hanen – see www.hanen.org
Move to Learn – www.movetolearn.com.au
Free downloads – www.movetolearn.com.au/content/free-interactive-ld-profile-test
– www.movetolearn.com.au/movetole/sites/default/files/pdf/WetMoveto Learn.pdf

NOTES

Food Intolerances – Dietary Tools

The last few articles focused on leveling the playing field for your child, giving him (or her) some of the tools that will help them get the most out of life.

But now to turn the spotlight on food allergies and intolerances; problems which often appear at the same time as the sensory differences become apparent. Which comes first is a moot point but, in my experience, some food intolerances can certainly increase sensitivity to sound (although they don't cause hyperacusis).

It is often said, "*we are what we eat*" but such a simplistic approach takes no account of individual differences. Indeed, the foods eaten are irrelevant unless the body is able to digest and process the food correctly – something that is certainly not the case for many children with ASD.

This is a contentious area partially because the effects on such children are often behavioral – so that the child (or adult) may become hyperactive or disruptive – often within one or two hours of eating.

The types of foods that have been implicated in this vary but include casein (found in milk), gluten (in wheat and other cereals) – as well as other foods, like chocolate, oranges, carrots and more.

These can sometimes result in quite bizarre behaviors from the little girl who would invariably begin to head-bang after drinking milk to the boy who, unobserved, ate a whole packet of Jaffa cakes, and then began swinging on the furniture and almost *"climbing the walls."*

The idea of food intolerances has been around since the 1980s but although some professionals advocate a dietary approach (often eliminating casein and gluten), others still dismiss the idea. Meanwhile some parents have seen the benefits for themselves, others have tried with scant success and some have tried only to abandon them as too restrictive.

We'll look at the casein/gluten free diets in the next article but if you feel that your child might be allergic to or intolerant of some food do seek professional advice wherever possible, especially if your child has constant stomach aches and other possible symptoms.

Meanwhile there are some simple steps that you might find helpful to take prior to implementing any elimination program.

These include:

- Keeping a daily diary. This should include the food eaten at each meal (and in-between meals, as well as any physical problems like stomach aches or unusual behaviors like head-banging or hyperactivity in the following 2 hours.

Giving thought to how you would implement the diet.

- If possible, involve the whole family in the diet as that means your child will not have to face the temptation of seeing his siblings (or you) eating foods he is not allowed to touch – or of knowing that there is a cake or jar of cookies in the cupboard.

- Implement any changes (or additions) SLOWLY – or you may run into problems as with the child who became "allergic to health food shops!"

- If you need to eliminate a particular food and change to another, do it gradually by adding a little bit of the new food to the old. For example, add a drop of rice milk to a glass of cow's milk, gradually increasing one and decreasing the other a drop or two at a time.

- If adding supplements introduce and build them up gradually so that the any possible adverse reactions are spotted.

- Alternate the most frequently eaten foods (and those to which you think he is intolerant) with other foods, so eventually he only eats them every third day.

Meanwhile you can also help support his digestive system by:

- Using organic or locally-sourced food where possible. This will reduce the number of additives consumed.
- Instead of eliminating cakes, biscuits and sweets, try organic or home-made products.
- Use the GI approach, which means opting for foods low on the glycaemic index.
- Some children benefit from avoiding food combinations, like eating proteins and carbohydrates together.
- Add a good probiotic to his diet.
- Provide a snack for mid-morning and mid-afternoon like a piece of fruit, fruit & nut bar etc.

NOTES

Elimination Diets – Join the Food Detectives

Diets. Do you flinch when you hear that word?

There's no need to – it's time-consuming but certainly not impossible.

Gluten and casein free (GF/CF) diets are often mentioned in relation to autism and yet some professionals are still skeptical about them.

Despite that it is a given that people from all walks of life suffer from those intolerances too – like Doug whose symptoms began with daily sickness when he drank milk. Even after cutting it out he gradually grew more sensitive to casein which caused fever, headaches, diarrhea and more: problems that were often triggered by products that were seemingly casein free.

Gluten too accounts for a whole range of chronic health conditions, as author Anne Sarkaisian, one of the leading authorities on the subject, tells us. Unlike many researchers she has even cured her own health problems by going gluten free.

In her book *Toxic Staple* Anne introduces us to Angela whose non-verbal, violent, non-interactive 3-year-old son responded almost miraculously to a GF/CF lifestyle.

Other parents too have found similar benefits: noting reduced physical symptoms like colic and pain and behavioral differences including improving sociability, communication, concentration and more. And yes, such accounts are certainly anecdotal but that doesn't invalidate them.

So if you feel a diet might help your child, it's certainly worth trying for it's one of those things that you'll probably always wonder about if you don't.

Anne Sarkaisian recommends that anyone thinking of a gluten free diet should get an AGA test (a simple medical test that measures sensitivity to gluten).

If that is not possible, do take advice from a registered dietitian who can help tailor the diet to meet your child's needs – and ensure he doesn't go short of vitamins and minerals.

Turning detective is seemingly hard when it comes to food for many processed foods have hidden gluten and casein – like fried foods dusted in flour (gluten), packaged mixes thickened with flour or soups and sauces that contain dairy products etc.

Top Tips for all diets

- Always think “CAN” not “can’t.”
- Use healthy, whole foods including vegetables, fruit, beans, grains, nuts, seeds, lean meats, poultry, and fish, quinoa, millet and rice noodles.
- There are some apps that can help. Some cover a range of foods while others address just one product like gluten. (If you find any of them helpful please share them in the comments.)
- Always read labels and remember that manufacturers can switch ingredients without notice.
- Asian, Indian, and Mexican foods can offer interesting alternatives like burritos and enchiladas made with corn or rice noodles.
- Try new things you haven’t tasted before. NB If new things are problematic for your child try eating them yourself when he is in the room and then leave them where he can get at them without effort.
- If your supermarket has a website you may find that it already offers a gluten/dairy/soy free alternatives. Even so many such lists don’t include their tinned or ready-made products – so if you belong to an autism group you may want to arrange to talk to/lobby someone in the grocery area for ask for help locating gluten-free products and putting them online or simply ask for more products if the choice isn’t broad enough.
- Use a personal “safe food list” when you go shopping.

“If in doubt, go without!”

Eating out?

- Check cafes/restaurants first and talk to them about what your child CAN eat – making sure they don't offer the things the child can't have like bread/milkshakes etc.
- Use:
  - o restaurants categorized as GFCF-friendly
  - o Vegetarian/vegan restaurants.
  - o Ethnic restaurants – Mexican, Japanese, Chinese, and Vietnamese.
  - o Kosher restaurants or "pareve" foods – which are dairy free.

Note: Before you begin it is also worth noting that new research has discovered that probiotics containing the Lactobacillus rhamnosus GG (LGG) bacteria have proved beneficial to toddlers and infants with milk allergies.

More information is available from:
PDF: https://www.tacanow.org/family-resources/gfcf-food-shopping-list/
http://toxicstaple.com/–re gluten

Children may enjoy http://www.glutenfreeghouls.com/home.html

Books
For children:
Gluten Free Friends Activity Book Kids – Nancy Patin Falini
Adam's Gluten Free Surprise – Debbie Simpson
Kids with Celiac Disease – Danna Korn

For parents
Diet Intervention and Autism Marilyn Le Breton
Toxic Staple: How Gluten May Be Wrecking Your Health – And What You Can Do About It! Anne Sarkaisian

NOTES

Other Potential Food “Hazards.” Still Detecting.

We’ve already discussed elimination diets in relation to the “usual (ASD related) suspects” gluten and casein. Even so there are other potential food “hazards” too that need investigating in case they are relevant to your child.

The first is personal so please bear with me while I tell you a story. You’re probably too young to have experienced this but for a moment I’d ask you to imagine that you are a woman of a certain age – just approaching that potentially tricky time of life when you expect to experience those embarrassing hot flushes – and worse.

What should you do? Follow the road of medication or try a more natural approach first? I choose the latter – trying out the potential benefits of soy. Delicious. So delicious in fact that I soon got hooked, eating more and more regardless of the fact that it is already commonplace in bread, ice-creams, chocolate and many convenience foods too.

Then came the headaches. The severe pounding in my head was often accompanied by nausea but initially I thought it was simply a variation of the migraines I have had since childhood.

But gradually I began to realize that the headaches were being triggered by some of the foods that I had eaten happily all my life – like porridge oats, marmite and even yoghurt. Strange! How could I suddenly be intolerant of so many different things – so much so that even the tiniest amount gave me an almost immediate headache?

During allergy tests I was asked if anything had changed in my diet – and the lightbulb flashed. Even so a long period of dieting followed; cutting out all soy products and all my known foods triggers. Now happily, as long as I steer clear of soy, I can eat anything and everything else without a problem.

So what of soy? Is it really good for us or should it, as a growing number of people believe, carry a health warning? Certainly by the early 1990s concern about the effects of soy-based baby formulas had escalated because of the possibility that soy might disrupt the hormones of infants – who are especially susceptible because of their immature immune systems. Those concerns have been translated into action by some countries who have banned the use of soy infant formula unless there is no alternative.

Amongst the many other reasons to avoid soy we find:

1) It can give rise to digestive problems and other problems because it contains:
   - enzyme inhibitors that block the enzymes needed for protein digestion.
   - compounds that can irritate the digestive tract.

2) Soy products are often highly processed making them much harder to igest.
3) Soy also contains lectins that may cause clumping of the red blood cells, which may also cause immunologic reactions.

Nor should we forget that while soy has been around for thousands of years there is a major difference in the way it is used in different parts of the world.

Today many countries use the soybean as an inexpensive product, low in carbohydrates and high in protein; eating it raw or cooked. And yet in Asia where it has been used for thousands of years it is always fermented before eating to make it more digestible.

The soy question also links in with Genetically Modified (GM) foods. One clinic which specializes in testing for food sensitivity found a 50 percent increase in soy allergies in 1998 the same year that GM beans came onto the world market. The researchers also noted that one of the soybean proteins most implicated in allergic reactions was far more concentrated in GM soybeans than in other crops.

My conclusion? Regardless of the ongoing debates over soy and GM products wherever possible I would suggest eliminating both soya and GM foods from infants" diets and also from those of children with ASD many of whom are far more vulnerable than other children. For more about the effects of soy see:

http://www.huffingtonpost.com/dr-mercola/soy-health_b_1822466.html
http://www.wholesoystory.com/

NOTES

Food Intolerances – And Finally

Earlier I mentioned a girl who became seemingly "drunk" after eating carrots and a boy who, after "scoffing" a whole packet of chocolate and orange biscuits became really hyperactive. Seemingly strange behaviors you might think and yet they are reasonably common amongst children on the Autism Spectrum as many parents will tell you.

So in the final lap of this dietary journey I'd like to introduce you to the possible cause of such behavior: which lies two specific natural chemicals: phenols (sometimes called phenolics) and salicylates.

Phenols are found in most foods – with man-made versions also being used in common non-foods like toothpaste, hair dyes, medicine, and disinfectants. Salicylates provide plants with protection from diseases and chemically are very similar to the man-made chemical commonly known as Aspirin.

Both can have a beneficial action in some people and yet, for some people with autism, both can be problematic.

How so? The answer came in the 1990s when a parental group called Allergy-induced Autism (AiA) suggested that the various changes associated with the late-onset autism that affected their children could be the final stage of a slow and almost invisible illness.

Their concern was that, although the onset of the autism was generally accompanied by various physical symptoms, the latter were generally ignored.

And because many of the families involved had members with a history of various allergic disorders including asthma, eczema, hay fever and migraine, they decided to ask researcher Dr Rosemary Waring from Birmingham University in the UK for her help.

To their surprise she and her colleagues found that, unlike age-matched controls, the children with autism had low levels of plasma sulfate: which helps trigger the production of hydrochloric acid and pepsin and prompts the release of two hormones – cholecystokinin and secretin.

They also found that some children with ASD had a deficiency of phenolsulphotransferase-P (PST-P), which leaves the body unable to process phenols, salicylates and chemicals of all kinds from food colorings and artificial flavorings to preservatives as well as to heavy metals. All of which certainly explains why some such children are intolerant of a variety of foods.

The symptoms that originally concerned the parents included:

- A dramatic change in diet with the child becoming intolerant to certain foods whilst craving others and/or an excessive thirst.
- Pale complexion; red face/ears, especially after eating. Dark rings under the eyes. Dry skin.
- Sweating excessively (especially at night).
- Bad catarrh.
- Diarrhea; bloating; stomach pains.
- Asthma; eczema; urticaria (nettle rash), an allergic reaction to some substance (often food).
- Temperature rises for no apparent reason.
- Hypoglycemia and possible petit mal epilepsy.

Other noteworthy symptoms of phenol intolerance include hyperactivity, aggression, headaches, head banging or other self-injury, inappropriate laughter and an inability to sleep at night: things which are often considered to be part of the child's autism.

Meanwhile reactions to salicylate-sensitivity often include difficulty breathing, wheezing, headache, nasal congestion, stomach pain, change in skin color as well as physical signs like hives, skin rash or urticarial or swelling of hands/feet/face.

The reactions compiled by the AiA suggest that some children are sensitive to both phenols and salicylates. So if you think your child might be affected by such things the simplest route is to take a look at the Feingold Diet, developed by the late Dr. Feingold.

Originally aimed at those with asthma and eczema its effect on behavior was noticed in the 1960s: a time when Western diets became saturated with food dyes and other additives. Such effects led to its widespread use with people with Attention Deficit/Hyperactivity Disorder as well as those on the Autism Spectrum.

While many dyes and additives have now been removed from our food phenols and salicylates remain. The Feingold Diet aims to eliminate them replacing them with similar foods – something that happily, still leaves a wide selection of foods to choose from.

To find out more about The Feingold Diet go to http://feingold.org/.

NOTES

Medication. A Spoonful of Sugar?

Now to the controversial area of medication. While it is certainly worth trying a sensory and dietary approach first it would be foolish to ignore the fact that the correct medication – given in the right amount – can help at times.

A sweeping statement? No. Firstly it is based on my own experience of seasonal affective disorder (SAD) – a depressive illness that tends to happen as the days get darker.

While in the past it has sometimes responded well to herbal remedies there have been some years when a stressful situation had compounded the SAD and I have found that the only way to alleviate the symptoms has been medication.

More importantly, some people on the autism spectrum like Temple Grandin and David Miedzianik have also found the correct medications to be beneficial in reducing their anxiety levels and associated difficulties.

Types of medications often used in treating people with ASD

If you've been following this series you will know that I believe that alleviating stress can help to reduce the symptoms of anxiety – and will, in turn, generally lessen "aggressive" behaviors, obsessive or compulsive behaviors – and more. Even so the choice of drug is individual and could include medications used to help obsessive or compulsive behaviors, hyperactivity, behavioral problems, depression or anxiety.

Some of the most common are:

- Drugs for anxiety disorders (e.g. beta blockers like propranolol)

- Selective serotonin re-uptake inhibitors (SSRIs) like fluoxetine (otherwise known as Prozac). These are used in the treatment of anxiety disorders and depression, in children and adults.
- Naltrexone – has been found to ease disabling repetitive and self-injurious behaviors in some children and adults with autism.
- Atypical antipsychotics (like risperidone), are often used to treat a variety of symptoms like irritability, aggression, self-injury hyperactivity and stereotyped behavior. These are frequently associated with sedation, especially early in the course of treatment.

Unfortunately people often misunderstand how drugs work. Several years ago one report described a careworker who, recklessly (and stupidly), tried some of the medication prescribed for one of his clients. Unsurprisingly it had a detrimental effect on him and so he reduced his client's medication without reference to the doctor: although how the sudden reduction affected his client was not recorded.

How they work:

- Each medication is designed to help with a specific problem so it won't produce similar results in a healthy person.
- The efficiency of our bodies to cope with medication also means that the dosage is individual.
- If you become accustomed to a particular drug your body may begin to eliminate it more efficiently, which is why the dosage may need to be increased at times.

Trying to make this decision for your child? It is especially difficult to remain objective, but as ever, quality of life is a crucial deciding factor. The child or adult who is constantly agitated is not going to be happy (any more than you would) and so, if the problem hasn't been alleviated by other means, medication may well have a vital part to play.

Top Tips

- If medication is suggested for your child don't simply dismiss the idea.
- Talk to your doctor both about the potential benefits and possible side effects and question the alternatives.
- Consider all the facts and discuss it with all concerned before you make a decision.

Remind your doctor that:

- Some people with autism don't react to medication as others might – so that tranquillizers for instance can often have the opposite effect to the one you expect. (Possible reasons include an underactive nervous system, metabolic differences, allergies or digestive problems).
- Some people with ASD react better to lower doses that to larger ones.

If you do opt for medication remember:

- The child with limited communication skills won't be able to tell you how he feels, so you need to monitor his reactions carefully.
- Use a daily diary to record all side effects (both good and bad) – as it is all too easy to forget exactly what happened when.
- Contact your doctor if you have any concerns/questions.
- Reductions/alterations in medication should take place under a doctor's supervision and need careful observation.

NOTES

SCHOOL

Starting or Going Back to School? Try these Tips.

Tips for Parents

It's always a good idea for parents to build a good relationship with the child's teacher – and to help them understand their child.

1) Before he begins school:

   - Visit the school yourself to meet the teacher and other staff.
   - Arrange for your child to meet the teacher and spend some time in the classroom, dining area etc.
   - See if the teacher can introduce you to some of the other families before school starts so that your child can get to know some of the other children who will be in his class.
   - Adjust your child's bedtime and waking, washing, breakfast routine and even lunchtime towards the school schedule.
   - Let him take a favorite object to school with him – making it age appropriate if possible (or pocket sized if not) as that will minimize the chances of bullying.

2) Do share information about your child. Every child is different so even if the teaching staff have worked with such children before it will help if you make an information sheet that include any or all of the following:

   - His strengths – attention to detail, skills/interests/obsessions that can be built on.

- ☐ His level of speech/verbal skills
- ☐ Level of understanding
- ☐ How he learns best – include points such as whether he is a visual thinker or learns better through touching and feeling things, or whether he simply needs time to assimilate information
- ☐ What helps him learn – quiet place, regular breaks, individual attention
- ☐ What he finds challenging – which might be noise, lights physical touch, finding other rooms and even the toilets etc.
- ☐ Any warning signs that would indicate when he is getting more stressed, overloaded, frustrated, etc.
- ☐ What the teacher can do to make learning easier – extra support at break times, a school buddy, sitting him at the front to minimize distractions etc.
- ☐ Any special requirements – like a gluten free diet or aids such as tinted lenses.
- ☐ Anything you have particular concerns about.

3) Keep a daily journal that can be shared between home and school. This – and the list above - can be:

   - ☐ used by all staff for reference;
   - ☐ updated as things change;
   - ☐ helpful for parent-teacher meetings.

4) Talk through problems and concerns as soon as they arise so that things don't fester.

NOTES

New Kid in the Class? A Positive Teacher's Quick Guide to Autism

Top Tips

1. All children live up (or down) to other people's expectations so be positive and realistic – as your attitude will affect much of the rest of his life.

2. Your job is to help him to fulfil his potential so always accentuate the positive.

3. Liaising with the parents is a vital part of that.

Be aware that:

1) Children with ASD are often more vulnerable to bulling than other children – and, because some of them may be socially naïve they can sometimes be manipulated by their peers.

2) The majority of children with ASD have a range of sensory differences that can make their lives very challenging. This can give rise to problem in several areas so that he may:

- only hear parts of a sentence.
- have hyperacusis and actually find some sounds painful – or hear things that you don't like the fan on an interactive white board.
- find physical touch painful – so don't touch him unless he can see that you are going to – or you tell him that you are going to.
- be extremely sensitive to some smells and tastes.
- have undiagnosed visual differences.

Such problems can:

- affect reading/writing – so do make allowances for his difficulties and don't expect the impossible like coloring within lines, writing neatly or reading out loud.

- make some patterns on clothing (like stripes) uncomfortable for him to look at.
- make walking down a corridor difficult.
- give him fragmented vision or even make him face-blind under some lighting conditions – much as it does when you walk into a room after being outside in bright sunlight.
- make eye contact painful.

Those problems can:

- Make him incredibly anxious
- Leave him unable to process more than one piece of info at a time – so don't expect – or force the child to make eye contact as that may make it hard for him to concentrate on what you are saying.
- Mean that in some situations – like a noisy room – he will be vulnerable to "overload." That can cause him to, make mistakes, get frustrated or have a melt-down or even fall asleep. If you allow him to take a break – preferably before he gets overloaded – he will be able to return re-focused.
- If he is already in overload, try not to touch or talk to him unless you have to as that can add to the stress.

DON'T TAKE THINGS PERSONALLY.

Sometimes problems arise because:

- He takes things literally and may not understand jokes, sarcasm etc.
- His sense of personal space is poor so he may impinge on others.
- He speaks his mind – and even though he doesn't mean to be impolite it can sometimes sound that way.
- Some (though not all) children have a severe form of social anxiety which can also impair their ability to communicate and interact with others.

Always try to preempt problems before they arise.

Note: Sometimes children will actually act out the feelings of those around them – including yours.

Stay calm and, if you feel that you are getting overwhelmed, do step away and take the time to calm down or take a break.

NOTES

BULLYING

Vulnerability

Children with ASD, like those with other disabilities, are more vulnerable than their peers and this is often compounded by their lack of awareness of others, visual problems and stereotyped behaviors.

Any of those things will make the child stand out and, by drawing attention to his differences, can make him the butt of jokes or lead to bullying which can make his life miserable.

As with all children being bullied can also cause a loss of self-esteem, depression or other mental health issues.

Bullying

Bullying can take many forms, from name-calling to social isolation and, sadly, even physical violence – which is usually the easiest to identify. Sometimes though the bully will pick up on the specific difficulties that such vulnerable children have and use them when bullying him.

Examples could include:

- using his naivety to encourage him to break the rules;
- “winding him up” or even causing a sensory overload - so that he becomes agitated/very anxious and:
    - acts in an apparently strange or inappropriate manner;
    - uses inappropriate language;
    - hits out/hurts another child;
- playing practical jokes that are intended to demean the person concerned – like one where a boy was asked to wear a silly costume to class on an ordinary school day.

Sadly, this can sometimes mean that it is your child who gets into trouble with the teacher while the bully escapes unscathed.

Unfortunately bullying is not always confined to children, for adults can be bullies too as some of us know to our cost. Another problem is that occasionally a member of staff will misinterpret ASD behaviors as “bad” behavior, and respond unhelpfully.

While those physical signs such as torn clothes, cuts and bruises are easy to see, the more subtle signs may be less easy to identify but could include changes in your child’s behavior such as:

☐ a reluctance to go to school;
☐ increased anxiety; verbal outbursts;
☐ physical abuse towards others or himself;
☐ reverting to bed-wetting;
☐ sudden (or increased) incontinence during the day;
☐ an increase in problem behaviors whilst at school.

Even so it is worth noting that while such changes can result from bullying they could have other causes too – such as a change of teacher/classroom etc., so do liaise with the school so that you can determine the cause(s).

Cyberbullying

While, historically, bullying has been a largely school-oriented phenomenon, cyberbullying and text-bullying is now on the increase and may be sent via e- mail, instant messaging or online communities such as Myspace and Facebook.

This allows bullies to torment, threaten, humiliate or embarrass their classmates, as Jesse A. Saperstein clearly describes in his best-selling memoir Atypical: Life with Asperger’s in 20 1/3 Chapters.

The older child/teenager who uses the Internet without support is obviously a possible prey to this awful form of bullying, so you may need to teach him how to protect himself

Top Tips

These will obviously vary according to the child’s age and ability so pick those that are most helpful:

If appropriate to your child encourage him to:

- ☐ *Talk about the problems* – to you, a guidance counsellor, teacher or friend — who can give the support needed. This is a good outlet for the fears and frustrations.
- ☐ *Hold the anger.* Explain that bullies want to control his emotions. Get him to try and write his feelings down instead (perhaps in story form?) – but do not let him share them with other people in his class.
- ☐ *Discourage physical reactions* - (No kicking, hitting, or pushing) as he cannot be sure what the bully will do in response and may get hurt or get into trouble.
- ☐ *Ignore the bully and walk away.* Explain that bullies thrive on the reaction they get and may eventually get bored trying to get a response.
- ☐ *How to advocate for himself*

Help him stand up for himself by suggesting that he:

1) **Practices confidence.**
   - ☐ Practice ways to respond to the bully – both verbally and through his behavior.
   - ☐ Help him practice feeling good about himself (even if he has to fake it at first).

2) **Takes charge of his life.**
   - ☐ Join a class, club, or gym to where he will meet new people and gain confidence.
   - ☐ Sharing an interest will also help him make friends.

3) **Walks tall and holds his head high.**

- Help him use body language to send a message that he's not vulnerable.
- Exercise is one way to feel strong and powerful so, if appropriate, you could suggest he learns a martial art, yoga or surfing etc.
- Alternatively he could hone his skills in something like chess, art, music, computers, or writing.

If the bullying occurs at school:

Some schools are still far handled more efficient at dealing with bullying than others but all should now have an anti-bullying policy in place that should be available on request.

The child's inability to recognize and/or deal with bullying makes it a special education issue and, as such, it can be addressed through your child's IEP (Individualized Education Program) if you feel that the school is not acting to remedy the situation – or is too slow to do so.

If so the IEP should note that you are concerned about the situation because:

- The child is more vulnerable than his peers
- He needs help with social skills
- The classroom teacher and other staff that are involved with him need to work together to help him learn:
    - how to identify different forms of bullying from exclusion to manipulation.
    - coping strategies.
    - appropriate responses - when to seek adult support and how to handle harassing confrontations.

Other Tips:

- Keep a record of all conversations so that you can refer back to them if necessary.
- Keep copies of your child's education records so that you can identify information that supports your position.

- ☐ Document good things by sending thank-you notes to the staff that say positive things about your child.

If the bully is a child:

- ☐ Discuss the problem/s with the teacher.
- ☐ Talk to the teacher about ensuring that your child does not find himself alone in places.
    - Ask her to set up a "buddy scheme" so that another child plays
    - with your child in the playground
    - Make all ancillary staff aware of his problems so that they can keep an eye on him will also be helpful.

If the teacher is guilty of bullying – and yes, sadly, that does happen at times:

- ☐ Don't react immediately unless there are serious safety concerns as it is better to think things through carefully and take advice if necessary.
- ☐ Discuss the problems with the head teacher and ask what action will be taken.
- ☐ Put your concerns in writing – and also ask for a written response as that will be useful documentation if you ever need to take further action.
- ☐ Document all the conversations you have - both the good and the bad.

See more at: http://www.wrightslaw.com/info/bully.teachers.

If you feel that further action is needed and live in the US, the following may also help: http://www.specialeducationadvisor.com/bullying-is-never-okay- how-to-use-a-gebser-letter/

Cyber Bullying and other internet perils

While historically, bullying has been a largely school-oriented phenomenon, cyber-bullying and text bullying is now on the increase. This allows bullies to torment, threaten, humiliate or embarrass their classmates via e-mail, instant messaging and through online communities such as Myspace and Facebook.

The teenager who is able to use the internet without support is obviously a possible prey to this awful form of bullying.

Protect your child from cyberbullying and worse:

- Where possible get involved with your child's online activities.
- Know all the passwords and make it a policy to check them regularly.
- If your child has an online web page, such as with MySpace, visit it frequently to see what he or she is posting.
- Print out anything that seems dubious.
- Use monitoring programs for the phone or computer. These will enable you to block inappropriate websites *and disable the camera to prevent sexting.* Some even come with a "Parent Dashboard" putting you in charge so that you can view texts and photos, switch apps on and off, view the contact history, block websites and even be alerted to specific contacts.
- Monitor your child's social media activity and print out anything that looks unusual or suspicious.
- Most computers have built in software to restrict your child's Internet usage – see user settings - but there are also a range of other programs for smartphones and tablets which include:
  - Mobile Guardian
  - My Mobile Watchdog
  - Mama Bear
  - Time Away

NOTES

Author's note.

Thanks for reading.

I do hope that you found some of the tips and hints helpful for your child.
If so please leave a positive review.

Please share this book with anyone who has need of it.

Thank you.

For more information about some of the difficulties found in autism please check out: www.autismdecoded.com or check out my other books.