

## **Living with autism: a family's perspective**

**by a parent of a child with autism**

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### **Editorial comment**

This paper is a transcript of a conference presentation given to research scientists at the Wellcome Trust by the mother of a 15 year old boy with autism. It gives a very moving and detailed account of her son's development over the years and her response to his diagnosis. He has attended a number of different schools and his parents have tried many interventions in their quest to help their son. The presentation seeks to explain why parents often try several different treatments and comments on the effects of some of these. The paper ends with a plea to those involved in research to conduct studies which will help the lives of children with autism and, in so doing, those of their family. The paper also serves to raise awareness and to act as a reminder to professionals to bear in mind the emotional and physical impact of autism on families when talking to parents and carers.

### **Introduction**

I have been asked to talk to you today about living with autism, which as a parent of an autistic child is something that I and my family do on a daily basis. It was not something we could have prepared for and was completely unexpected - indeed, before my son's diagnosis I do not think I knew anything much about autism.

Why had it happened to us and where had it come from? I think both my husband and I have secretly pondered this question - not to apportion blame but just because it was such unknown territory and was not what we had envisaged when setting out to raise a family.

My son is now 15 years old and was diagnosed with high functioning autism when he was around 5 years of age. The diagnosis was made by an autism specialist and was

one which I really fought against. I remember leaving the hospital in London, incandescent with rage – after all what did they know? They must be wrong? This couldn't be true – we simply didn't have it in the family.

I was convinced he had a speech and language disorder (pure and simple). In fact, from what I had read, I thought it had to be semantic pragmatic language disorder...(in fact anything but autism).

I think the specialist could tell I was upset by the finality of the diagnosis and I remember their parting shot as we left .... "well call it Asperger Syndrome if it makes you feel better". It did - and for a while that was how I referred to it..... and I started to read, any book I could, about Asperger Syndrome and (of course semantic pragmatic language disorder) which was the term I really liked.

Why did I prefer these two conditions? Well as far as I could work out the outcomes seemed better for either of them – better than I could hope for from autism. I felt there was hope in the Asperger diagnosis. The image conjured up by autism seemed bleaker. In my mind, Asperger syndrome spoke of the eccentric, the highly intelligent, loners, people who are just a bit 'odd'.

I imagine that different parents will have a variety of reactions to the diagnosis, when it comes. Whether my perceptions about autism were right or not is relatively unimportant. This was just how I felt at the time and my inability to accept it in the beginning was I think my way of coping and adjusting to something quite difficult.

I probably settled to the reality of the diagnosis when my son was around 9 years of age (ie four years after the diagnosis). Up until that time I kept on looking for other answers to his unusual development.

Of course, over the years I have got to know quite a few parents of autistic children, some of whom have children with very low functioning autism. Our experiences are as wide and varied as our individual children and yet we are bound by one essential search – to help them make sense of a difficult and changing world – something they are really ill-equipped to do.

### **Early development**

So what about his early development? He was born via an elective Caesarean section as I had developed gestational diabetes (which went largely undiagnosed throughout the

pregnancy, but that is another story). All went well with the delivery and, once over, I imagined life would be plain sailing. However, from about the first or second week I began to think my son was a little unusual. He seemed so restless and just would not sleep. Even as a tiny baby, only weeks old, he seemed to need entertaining. He was alert. Any slight noise in the house would wake him up (the creak of a floor board, for example).

We lived on tenter hooks afraid he would wake up when we had just got him to sleep. It was exhausting. I was constantly tired.

This sleeping pattern (napping for 20 minutes at a time) continued for the first 6 months. At the time we were living in Northern Ireland (it was rainy and very damp) and during the first 4 months I remember him having continual ear infections and colds which were treated with antibiotics – something which I later wondered about as a possible contributor to this mysterious condition.

He walked early (by 11 months) and once on his feet he became a bigger nightmare. He was extremely active, climbing out of play pens, and working out how to escape from any 'prison' we may try to construct to keep him safe. My mother-in-law stated many a time that he was just like his father (who had been a very hyperactive child and is still a bit of a hyperactive adult today). It was probably around this time that the bouncing began.... We would be woken most mornings by the sound of him bouncing in his cot, whilst holding on to the bars. So much energy. This continued for some time and is still a feature today. The noise of my son bouncing and stamping around the bathroom and his bedroom accompanied by so many different sounds and noises (echolalia and grunts) can be heard all over the house.

During his early years I was sure I was dealing with a hyperactive, gifted and talented child who would play rugby for England. The hyperactivity continued along with a slight, headstrong streak of obstinacy .

He began to become a little less cooperative. The house however, began to resemble a prison, as locks were fitted on fridges, cupboards, external gates, doors ... in fact all over the place.

It was around the age of two years, that I noticed he was not talking. Other children of his age were putting words together. He had a few words. He would ask for 'juice' and could say 'mama' and 'dada' but didn't choose to use them often. The health visitor suggested we took him to a speech and language therapist (after checking out his

hearing which proved normal). The conclusion was that he probably had a little speech and language delay.

By two and a half he still wasn't talking and the words 'speech and language disorder' with 'mild autistic features' were uttered for the first time. I am by nature a worrier and also someone who has to fix things the moment they go wrong. These characteristics do not make for an easy ride when dealing with autism.

I did not like the term 'mild autistic features' and promptly took him to see a private specialist to get the diagnosis I think I wanted at this time which was ADHD (Attention Deficit Hyperactivity Disorder). My son obliged by refusing to sit still and moving around the consultant's rooms as though possessed.

I got the diagnosis I wanted and breathed a sigh of relief. After all, doctors can do things for ADHD – there is medication (not like autism) - so ADHD had got to be better-hadn't it?.

By this time we had left Northern Ireland and were living in Gloucestershire where my son was referred to a nursery specialising in children with language disorders. As a result, during his early years, he did receive some quite significant speech and language therapy input. His language improved very slightly but not as much as I would have liked and as he approached 5 years of age we were on the move again. We left Gloucestershire for Germany.

Five years of age brought the dreaded issue of school. I knew it would be difficult and naturally it was. He would not sit still. He could not really talk or understand anyone which was why he probably didn't sit still. Everything there was a complete irrelevance to him.

The teacher struggled and he began school life only doing 5 mornings a week (even though he was placed in a special language unit attached to the school). I remember there was another child in the unit with autism but he seemed to be managing better than my son as he was generally more compliant.

My son learned to read. He was not a bad reader as he has very good visual skills. Although he was reading the words, his comprehension was poor. He did not volunteer any conversation. Any dialogue was one-sided with him providing one word answers to questions. He did not (indeed still does not) write anything imaginative or descriptive. He hated school.

We returned to England when he was six and managed to get a statement of special educational needs. Armed with this statement, which I had checked and re-checked before agreeing to, he was again placed in a language unit attached to a school. This proved to be a terrible mistake. The teacher had absolutely no idea how to handle children with autism and was an utter disaster. She would drag him onto the playground at the end of the day announcing (to me and all the other assembled parents) that he had had yet another bad day and the catalogue of disasters would be reeled off. They all centred around his odd and challenging behaviour.

He stayed there for a year and with hindsight we should have moved him earlier, but you feel very vulnerable as a parent and I was still at the stage of wanting to keep him in mainstream. In my mind, the longer he was in a language unit, the longer the problem was one of language and not of autism.

Running as fast as we could from this school, we got an exasperated LEA (Local Education Authority) to place him in an independent school run by a speech and language charity. We were all much happier here and things began to settle down a bit. All the children had significant language problems. There were even a number with autism and the teachers were trained in language difficulties. I think he did improve at this school and he stayed there until he had to leave at the age of 11. His self-esteem definitely improved.

By this time I was beginning to come to terms with the autism, and having toyed again with ADHD when he was about 9, I think I finally gave up the fight and began to use the term autistic and my son in the same sentence. His sleeping pattern which had been so poor as a baby continued to be erratic during his infant and junior school years. He was difficult to get to sleep (often staying awake until midnight). However, once asleep he did usually stay so (which was a blessing).

At the age of 11, he transferred to a local authority school which specialised in autism and this is where he is now. The school is fantastic - full of very good teachers and my son is relatively happy there.

## **Issues which affect our family life the most**

So what are the issues and behaviours which affect us the most? We feel generally quite lucky as over the last couple of years, he has made some improvements. I think with maturity a number of things are beginning to fall into place for him.

However, that having been said, one of his biggest problems is his **behaviour in a social context**. At home and in the family we can accommodate all his eccentricities. Out in the real world, things are a lot more difficult and I worry most about this. I worry mainly that some of his actions will be misinterpreted and this could leave him very vulnerable.

His **eye-contact** is not great. He will look at you if you tell him to, but he doesn't do it naturally. He invades people's personal space. He gets up too close (whether he knows you or not). He talks to himself a lot. You can hear him all over the house repeating anything which has been said to him or he has heard on the TV or in a video game. His **speech** is odd and a little eccentric. He speaks in a very authoritarian way almost as if he is giving commands.

At home he is **constantly moving**. He doesn't often sit and relax in front of the TV. He tends to pace from the kitchen into the hall and into the drawing room and back again, talking to himself. It is exhausting for us and it must be exhausting for him. He also does this in school and I know it is an issue for them too. He jumps and bounces on the spot when excited.

**Fear** is often an underlying cause of many of his behaviours. He seems to live in a state of constant anxiety that someone will do something which will either annoy him or hurt his ears. He finds high-pitched sounds a constant source of worry. He is afraid of growing up; and has a short fuse and will lash out when angry or irritated – (particularly at his sister).

His unpredictable nature and his obsessive behaviour mean that we have to negotiate and prepare for social trips and outings.

For us it is the **obsessive behaviour** which is proving to be the biggest barrier to his progress and personal development. Although as a very small child I do not really recall him lining his toys up in straight lines or particularly looking for order, this feature has developed over time. It started when he was about 7 and he would become obsessed with a particular topic or subject. I remember obsessions about trees, big cats, space, the Power Puff Girls, mushrooms, the Incredibles, and children's car booster seats

amongst others. He now obsesses over the Robin Hood TV series, Dr Who of course and Playstation and video games.

The practical difficulty in taking him out and about with these obsessions is huge. When babies and toddlers cry in supermarkets or cafes, he can be heard to shout 'shut up' at the offending baby or child. When he looks relatively normal and speaks quite coherently this is often misunderstood for extreme rudeness or worse.

As a result, my husband and I (and anyone else who is taking him out) has to be on the look out for babies and we will avoid shops or finish our drinks quickly in case any infant should cry.

When unavoidably caught out (such as standing at a till waiting to pay for an item when the infant cries), I have to keep reminding him not to shout and will keep talking to him to keep him calm.

Car booster seats are currently proving to be a big issue. My son wants to be the same as his younger cousins. This could be to do with a general fear of growing of up. Some of these cousins still use car booster seats. Obviously at 15 he does not need one, and we have had one almighty battle to keep him out of one. If any child aged 7 upwards comes to our house, he will often run to get a tape measure to check their height. He knows by law that you have to be in a booster seat until you are 4 foot 5 inches tall.

Many a new child to our house has been surprised by the tape measure trick and woe betide them if they are in a booster seat when they are over this height.

These are funny and amusing stories but they do cause us severe stress. Pretend shooting at parents in the street as they load their infants into a car seat is often very difficult to explain.

His knowledge of language has improved but I feel like a walking dictionary.

His obsessive questioning (what does such or such a word mean?) even though he has asked this question a hundred times before and he has heard the answer just as many times, drives me to distraction. Most children when learning to speak may do this for a few months or so (around toddlerhood) - my son has been doing it for years and years. The same questions asked again and again and if you decide not to answer he will just ask them again.

His obsession with words has led him to read a dictionary from cover to cover, making note of every swear word he comes across. The problem now is that he has a very wide

vocabulary with some choice words but lacks the ability, and instinct, to understand the impact that these words have on certain people – teachers, the elderly, very young children, grannies!! Sometimes I think he says these words just to see what an individual's reaction will be.

Generally speaking as a family, when we go out in public or do anything really, everything comes back to my son. It always has done. Are the people we are seeing aware of him and his problems? Is the place we are going to able to accommodate his eccentricities? (such as no crying babies, no booster seats, no-one who may be offended easily by swear words and so on).

When situations fail these 'suitability tests', grandparents may be called in to child mind. Internet supermarket delivery services have certainly made my life easier (if a little more expensive).

But it is not all gloom and despair. He does have an odd and quirky sense of humour and does laugh – albeit at his own jokes rather than anyone else's. When you ask him to explain some of his emotions he can do so using his highly individual language. I once asked him something about numbers, to find that for him, letters and numbers are all colours. (*"That's what they look like in my brain"*). Each number he views in terms of a colour (number 1 is white whilst 20 is red). He is quite fascinating at times and because he can express himself, I hope he may be able to tell us quite a lot about being autistic.

## **Vulnerability**

I have just given you a brief outline of my son's life to date and the impact that he and his behaviours have had on our family. Vulnerability plays a big part in the lives of people with autism and yet they are not the only ones who are vulnerable. Parents of autistic individuals can also be extremely vulnerable.

Over the years I have attended a number of autism related conferences and workshops.

I have at times been dismayed to hear speakers talking with incredulity about the amount of money some parents spend on weird and alternative therapies (the implication being that they are gullible). I like to think that I am not an unintelligent person and yet I like many others have spent funds and invested time and emotion in taking my son off for many alternative therapies.

Some examples of those I have attempted include – (and I may have forgotten some):

- Removal of additives and preservatives from his diet.
- Removal of monosodium glutamate from his diet
- Hair analysis – to see if he had low levels of zinc or high levels of anything else
- Vitamin B6, B12, magnesium and zinc supplements
- Fish oils – I have given him Omega 3 and 6 supplements
- Evening Primrose Oil
- Nystatin to treat Candida; this came from a visit to a doctor who was treating other autistic children by this method (with some success). The link to my undiagnosed diabetes and the fact that he would eat handfuls of sugar as an infant (and still adores anything sweet) made me think this could be an issue for him. I have replaced sugar with sweetener.
- The theory of a leaky gut was one I thought seemed reasonable and given the issue with the numerous antibiotics which he had when only months old was one I thought might fit with my son. As a result I have sent samples off to labs to see if he could have intolerances to gluten and casein. As a result of this analysis, we started a gluten and casein free diet but this proved just too difficult to administer and seemed to have little effect so I gave up on it.
- We have tried cranial osteopathy. We went on numerous visits to a children's osteopathic centre where he would have his skull manipulated. This cost at least £25 a session, not including the rail fare.
- We have tried a variety of other unusual therapies – often costly - involving manipulation of various parts of the body together with vitamin and mineral supplements.
- We have visited a learning assessment centre - this cost hundreds of pounds a time . This was to assess whether my son had ADHD alongside his autism. He was treated with Ritalin which made him worse. He lost weight and seemed to become spaced out. We discontinued this.
- Then he was given low doses of Prozac to help with his obsessive behaviour. The dosage he was on did not seem to make any difference and I ditched this as I had all of the others. However, I have seen reports in a recent broadsheet paper quoting an American doctor saying that all autistic children should be treated with Prozac. Perhaps I will look at this again?

That's how easy it is - you read something and you are off chasing another wild goose ...  
Or is it?

I think that parents, who in their desperation try any of these, should not be sneered at. It is precisely because scientists do not know exactly what causes autism and have no

cures or treatments that we parents do what we do. My overriding thought with all these treatments has been "what if this could have helped and I did not give it a go?"

## **Concluding comments**

### **What science can do? How you can help?**

So where does **all this lead us?** Well it has led me to become a fundraiser for an autism charity in the belief that I am doing something to raise the profile of autism whilst raising funds to enable scientists to learn more about it. But what can be done and how can you help? – because however interesting your test tubes, genes, proteins, neurons etc may be, there has to be a reason for doing what you are doing, which from a parent's perspective should not just be the advancement of scientific knowledge for its own sake. Surely that reason must be to translate science into some form of practical help (whether therapies, treatment or better educational support). Families need practical support to make life easier for both the individual with autism and themselves.

What would make my son's life easier? If you had asked me this question at various points over the last 15 years I may have given different answers.

However, the answer which I categorically give today is help with his obsessive disorder. I really feel this is stopping him learning and interacting more appropriately. He is consumed with thoughts about his games, crying babies and booster seats to the point that he finds it hard to concentrate and focus on anything else. He has other odd habits (such as touching various things a set number of times) and a few rituals. A more stable behavioural profile would I believe help him enormously. He is obviously intelligent – he just seems to be wired up in a very unusual way. I, for one, would love to see more research into unlocking this obsessive behaviour and freeing his mind to concentrate on more important things, - helping him see the bigger picture.

In common with all autistic people, he also has serious problems with empathy. So many times he fails to put himself in someone else's shoes. He does not do this naturally or instinctively and this inability will I think have a profound effect on his life chances. In a world where we operate in social groups, where being part of the 'in crowd' seems important, being a constant outsider must make for a lonely life.

Perhaps less able individuals with autism will not feel the lack of it but for those with high functioning autism it will be an issue which could lead to mental health problems.

He would also benefit from help to relieve his various anxieties and also from a whole host of social skills programmes, which I hope can be better designed the more we know about how the autistic brain works.

What skills do you need to be a parent of someone with autism? I don't know exactly. They and we are all so different, but a sense of humour, tenacity and a great deal of patience would probably not go amiss.

Whatever line of research you are involved in, I am sure that your work will prove instrumental in unlocking the causes of this fascinating (yet at times heart-breaking) disorder and I, as a parent, thank you for what you are doing and wish you all the very best of luck. Your work will touch millions.

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