

Ketchup Labels On Dinner Tables

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Autism; the 'A' word which conjures up distinct images. How many people think of Dustin Hoffman in the Rain Man or know of someone with a child who sits, trance-like, in the corner of a room rocking to and fro ("no sort of a life, God love him") when they think of autism?

The fact is, autism is a term for a range of communication and social behaviour disorders. My 9 year old daughter has Asperger Syndrome (AS), a form of autism recognised only within the last 5 years by the medical profession and it affects the way she interacts with people and situations encountered daily. Aimee has problems answering the 'wh' questions, like 'who', 'what' and 'why', and when things get too much for her she takes refuge in her books (a disorder which has now been given the name of hyperlexia). Her reading ability is that of a 13 year old but her understanding of what she reads is that of a 7 year old, a contradiction which causes her lots of frustration when she is asked about the story line in the book she is reading. Her obsession with reading can cause some terse moments, such as when you realise that she hasn't heard a word you have said to her at the dinner table because she has spent the last 10 minutes reading the ingredients label on the ketchup bottle ! She also has difficulty interacting with her peers, as she does not have the ability to 'read' social cues which are so obvious to her friends. She will talk incessantly to someone about her current obsession, e.g. small toy animals, and not realise that they have no interest in what she is saying, even when they walk off.

Aimee was first diagnosed with AS at the age of 7 and although I had known for a while that she had some sort of communication and understanding problem, the diagnosis of autism hit me like a ton of bricks. I suppose that at the back of my mind was the thought that she was suffering from a temporary behavioural problem which could be cured by a simple daily dose of megavitamins or minerals and then a miracle would occur and Aimee would suddenly be normal - whatever normal is. My mind was reeling and it took time for me to look into what we could do as a family and what Aimee could do as an individual to achieve the best outcome considering the diagnosis of autism.

Living with Asperger Syndrome is a challenge for us as a family and for Aimee as an individual. It is a challenge which we may never fully overcome but we aim to do the best we can. There is plenty of advice and help available and it is important to use common sense when deciding what to accept and what to ignore. As Aimee grows older she encounters more and more situations which she has to deal with herself and can be difficult for us to give her advice about what to do as she has difficulty relating exactly what happened in such awkward situations. Patience is often the key - not always easy when you meet her at the school gates and she can't remember what she has been doing during that day. Allowing her extra time to think about and make sense of what happened helps but we have to accept that there are instances which she will never be able to relate to us because she simply can't remember or understand them.

Education can be a big problem, although I was lucky enough to move near a wonderful primary school where the staff was aware of and sympathetic to Aimee's difficulties. They even fought for her to get extra help in the classroom, something for which I am eternally grateful, although for people who are not as fortunate as myself I would strongly advise that you fight, fight, fight. The first school Aimee attended would not admit there was a problem, although I did manage to get an educational psychologist to see Aimee. Unfortunately the psychologist only made things worse as she blamed me for Aimee's difficulties and said that my parenting expectations were unrealistic (I expected Aimee to join in some of the classroom activities in Year One). Since that disastrous interview I have learned not to be browbeaten into giving answers the 'experts' want and to be clear and concise about what Aimee needs in the way of extra help and understanding. Of course, there are times when I get upset, but she is my daughter after all and I am only human. Another problem which is often overlooked is that of poor co-ordination which often affects those with AS. In order to achieve certain skills we have to break them down into stages and concentrate on one stage at a time - you'd be surprised at how many stages there are in learning to propel yourself on a garden swing, but oh, the look of triumphant joy on Aimee's face when she finally masters a skill!

As with all other parents, I worry about what the future will bring and how Aimee will face new situations and adapt to new environments. She will be starting high school in less than 2 years and it is a big enough step for any child, let alone one with AS like Aimee. She will be allowed out of the school for lunchtimes and as her sense of danger when crossing the road and even talking to complete strangers is not age appropriate, I worry for her personal safety. On a social note I worry that she could be bullied with such a diverse age group within the high school and the sheer number of pupils, teachers and different lessons in different classrooms may be too much for her to cope with. For now though, we will concentrate less on reading the ketchup labels and more on what we can do to make it easier for Aimee to interact successfully with her surroundings.