Living with a child who has ADHD and special needs - a parent's perspective

Mrs Deborah Townson, author.

"He's just got Character!"

That's what my husband used to say to me when I rang him at work for some much needed adult conversation and support after another exhausting day with our son Jake.

Jake is now nearly 12 years old and has still got bags full of what we call character. He was born just before Christmas 1999 after a difficult pregnancy and birth but was average weight and healthy. Specialists have since stated to us that a difficult pregnancy can play a part in your a child's development and I sometimes wonder if injecting myself every day with heparin (due to having lupus) had any bearing on Jake's development. We were also told that genetics play a part and my family medical history is certainly colourful. My mum was sent away as a child several times to convalesce and was put on tranquilizers because of a diagnosis of St. Vitus dance, a condition involving involuntary movements. In addition, my sister, my cousin and I had what were called 'funny habits' as children. I believe we all have some traits of the things that Jacob has since been diagnosed with. Jake was diagnosed at the age of 5 with ADHD, OCD, Tourette syndrome, dyspraxia, autism, tip-toe walking (gait and tendon problems) and neurodevelopmental delay. I still remember the day my husband and I walked out of the consultant's office both stunned and speechless. We knew that Jacob was different and quirky but when someone actually labels your child and tells you that they will not be able to do certain things in their life that is a different matter. It then becomes real in some way and you feel like you have lost your child and he has suddenly become someone different that you do not now know. I remember talking, discussing and worrying over the same questions for days; we felt like our whole lives had changed just because of a few words a consultant had uttered that day. My husband buried his head in the sand and I became the practical one, researching everything on the internet. In the end, however, after talking to various specialists, other parents and various support groups and associations, you realize that you have to deal with the issues you face yourself. Talking to other parents, which is the best medicine ever, helps you focus on the fact that every child is different even if they are diagnosed with the same condition; your child is still an individual. You and only you have to find your own individual way of helping and guiding your own child through their milestones in life. What works for Jacob might not work for another child. You can certainly exchange helpful tips and tried and tested methods from other parents and give them a go but in the end some things may work and not others. In fact, some things may work on some days and not others. That is a big point to make. You think you have found a solution to a particular issue then the next day that solution sends Jacob into a rage or an emotional wreck. We have found, to our detriment on many occasions, that bribery, not reward charts are a great tool to use, even if it does cost us a fortune!

Within the first couple of years of Jake's life we knew that there was something different and quirky about him. I was a stay-at-home mum and it was exhausting, challenging but also rewarding on a daily basis looking after Jake. He never slept during the day, I remember driving or walking around for hours. He never liked to lie down or just sit. He wanted to be picked up or held all of the time. My hips would be aching by the end of the day! To this day Jake has never fallen asleep on the sofa in front of the television like other children and, apart from the times when he had measles and chickenpox, he has never slept during the day in his whole 12 years. He also never sleeps on car journeys. We have travelled to France and Scotland in the car and he was awake the whole time. Again this is very draining and stressful as you need to make sure you have enough things to entertain Jake for the whole journey but more importantly 9-10 hours of Jake talking, singing and tapping is very draining! When Jake has been ill or just overtired due to recurring bad nights or general lack of sleep he never catches up and gets very stressed and irritable. This is when he becomes uncontrollable with either outbursts of rage or emotion. He has damaged doors in the house and broken items and toys in these outbursts. He is so frustrated and upset with himself afterwards for doing it, he has often asked: "Why do I do this?"

It would also take Jake ages to settle at night. As a baby we would be stroking him for hours and as he has got older he would often say that he felt 'weird' and could not explain how he felt. This then led to endless talking and calming down. He would also wake several times during the night, and still does, again saying he feels weird or with pains in his legs. He has tight tendons and foot problems, sees an Orthotic Consultant and has physiotherapy for this but his sleep problems mean that my husband and I both feel like zombies most of the time; it's surprising we are still together!

Jake's appetite has always been very poor. As a baby it would take him twice as long to finish a bottle. Weaning was a nightmare. He would sit for hours in his high chair just pushing the food around or plastering the walls with it! He just grazed on little 'picky bits' as we called them. We developed a system, as he got older, that we called 'play and eat'. Jake would never sit still at the table so we would put food on a plate on the table and he would take a bite then go and play then return etc. This was the only way we could get him to eat as he was always too busy and too interested in moving to eat. Where he got his everlasting energy from we did not know and still don't to this day. We often compare him to the Duracell bunny! This obviously made it difficult to go out as a family or to places where people did not know us and Jake. He was always very active and into everything right from the word go. He was a very inquisitive baby and was walking by 10 months. He talked very early and everyone commented on his speech. In fact, the incessant non-stop talking drives you to distraction and still does today, along with his need to either be singing, pawing all over you or tapping or banging on something. We have since brought Jake a set of drums so that his banging and tapping can be channelled, hopefully into something constructive!

I met up with my ante-natal group on a weekly basis with our babies and started to compare Jake with the others. What a fatal mistake that was! Jake would never just lie under his baby gym, sit still or sleep in my arms like my friends' babies did. He would be wandering around the house looking in cupboards, eating cat food, running up and down stairs or just doing his usual talking. He would never leave your side. I remember frequently having to go to the toilet with him on my lap. If I got the chance to take a shower he would be in the bathroom with me. This separation anxiety has got worse as Jake has got older. It started with him hanging onto my legs when we first tried playgroup and school. It took weeks for him to settle and he still has issues at the start of every new term. Now it has got to the point of his not wanting to go into a different room or up the stairs without me. He will not go to the local shop on his own or with friends; he will not even go into a shop on his own if I am not with him. He will not stay in a car on his own whilst I fill up with petrol, let me post a letter or run into a shop without him, even if he has a friend in the car with him. This again obviously puts great demands on trying to complete even the simplest of tasks.

Jake has never been good at playing on his own. He constantly wants my attention and company and I have to do everything with him. This has consequently meant that is has been difficult to have a conversation with other people or do household tasks if I am on my own with him. As Jake has got older this has had more of an impact when trying to teach him to be independent as projects for school, homework, even washing, dressing, brushing teeth and normal day to day activities have to be done with one of us. Jake cannot tackle a task without that level of support, which makes life very stressful and demanding at all times. Jake receives a lot of emotional and practical support whilst in school and together we try to work on strategies that will help him try to become more independent. However, he does have a lot of issues to contend with, so again this is an ongoing project. Jake is also not good at making friends and has never approached others in play or for company. As parents, we have always had to instigate this on his behalf. Due to his anxieties about almost everything, he lacks confidence and self-esteem, needing constant reassurance and praise. Luckily Jake has built up a good group of friends since playgroup, who accept him for who he is. He is a kind and caring boy with a sensitive nature. He cannot see the bad in anyone and cannot understand when anyone is nasty to him. This obviously has its problems as he is very trusting of people and lives in a world where he thinks everything is safe and just. His sense of fair play has been evident since early on and, although he has his issues, he has been compassionate towards others who also have difficulties.

As well as Jake's hyperactivity, his little quirks and habits were also evident at an early stage. Jake easily becomes obsessed with anything and once a habit sets in you cannot get out of it. He could not and

still cannot go anywhere or to bed without his numerous toys or objects, especially his "sad tissues" (tissues that have been used if he is upset). He surrounds himself in bed with these objects and when we go out or away on holiday, he has certain rituals that have to be completed at bedtime and when getting dressed. These have to continue wherever we are. Again, no respite! When he was a toddler he used to sit in the washing basket or in cardboard boxes with this stuff and pretend to be an animal or some sort of creature. He has a vivid imagination. At parents evening, his first teacher mentioned to us that Jake had an extraordinary imagination as when all the children were asked to name their favourite animal the others mentioned cats and dogs Jake replied his favourite was a chameleon! He has favourite even numbers; odd numbers are the work of the devil! He likes objects to be in a certain positions. Again this causes him problems at school with concentration in lessons and when trying to complete day-to-day tasks.

He has had various tics since early on, from spitting, excessive nose-blowing to the point of bad nose bleeds, constant coughing (we had some comments made to us once whilst in a theatre - "Can't you shut that child up"), head-shaking resulting in bad headaches, coprolalia, pulling at clothes, scratching and making himself bleed, looking up at the sun to the extent that we had to take him to the opticians who prescribed reactive glasses, eye-blinking, clothes-pulling and the list could go on! These tics, for Jake, can make normal everyday tasks difficult but more importantly it's about social acceptance. We try to come up with strategies to divert attention away from Jake's current tic of the time. We just try to encourage him to talk about how it makes him feel and laugh about it together. Otherwise we would constantly end up crying about it.

I think overall the best piece of advice we could give any parent facing the diagnosis of any disability is to join as many support groups and associations as you can. Parents that have already experienced and been through what you are about to encounter are your saviours. They know exactly what you are talking about and will know how to point you in the right direction for help. Obviously you need to seek advice from specialists and make sure your communication with school is constant but nobody knows your child like you do and you need to come up with your own strategies that work for you. It is hard work and can be tiring and frustrating. Parents need more of a voice when it comes to legislation with regard to children with disabilities. We are the ones that live with them 24 hours a day and I often say I am going to video a day in our life just so other people can see how demanding it can actually be. Life with Jake continues to be demanding and sometimes very frustrating but it is also very rewarding. He is our son and we would not change him for the world.

GP Comment.

What have I learned from this paper?

This is a moving and very personal account of what it is like to live with a child who has not only ADHD but other special needs.

The paper raises several issues for the GP. These include the following.

1. The doctor and professional team not only have the task of providing a diagnosis, they also need to face the challenge of supporting the family with the implications of the diagnosis.

2. There has often been a delay before professionals have made a diagnosis of ADHD, despite families continually asserting that there was something wrong with the child.

3. Although it would be unwise to generalise, it is not unusual for fathers to be in denial with regard to ADHD or other special needs and for the mother to be left with the task of coping with the demands.

4. The sleep disturbance that often accompanies ADHD affects not only the child but the whole family. The comment of Jake's mother that she and her husband "both feel like zombies most of the time" was very telling.

5. The emphasis on the importance of parents identifying sources of support seems very appropriate.

6. The lack of understanding that other people often have of ADHD can be very hurtful for parents, especially when inappropriate comments are made.

7. Above all, it is an inspiration to see how parents can continue to love a child despite the extraordinary demands that he places on them; this makes us very aware that, as professionals, we must endeavour to understand the extent of the pressures that are placed on families and that we must do whatever we can to support them.

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