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Big issues for Little Man

*Life with a child on the autistic spectrum can be many things, but easy isn't one of them, as **Claire Louise Parkinson** can testify*

It's a little after 4am. I hear a commotion taking place downstairs and I get up to investigate. No, I'm not greeted by masked burglars, but instead by my ten-year-old son attempting to cook himself his favourite bacon as an early hours snack.

My son hasn't woken up hungry and yes, he was given his dinner the evening before. The truth is he hasn't actually been to sleep at all. Is this a first? Sadly, no, it happens to be a nightly occurrence.

My son, AKA Little Man, has Asperger's syndrome, a condition that makes up part of the autistic spectrum. Some refer to it as a milder form of autism but, for me, the word "mild" is a misleading description. You see, my child can speak and has done so from a very early age. He met most of his developmental milestones, even exceeding a few. Yet, his inability to communicate without confusion and misunderstandings, his poor social interaction that makes it hard to mix

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and play alongside other children, and the heightened anxiety that he exhibits when faced with unfamiliar situations and environments are all very apparent.

Here, then, is my predicament: do I (a) stand and cook this unhealthy snack at this ghastly hour, or (b) refuse, maybe offering a smaller, lighter alternative in its place, thereby running the risk of a possible early hours meltdown? For many, (a) would seem to be the harder option, standing cooking rashers of smoky bacon into the night, but for me this would have been easier. Nonetheless, (b) was my choice, which meant that Little Man wasn't best pleased.

Little Man isn't an only child; he actually has two younger siblings. His sister of eight, who could tell you a thing or two about having a brother with Asperger's, is now stood beside me looking tired and moderately unhappy at being woken some three and a half hours earlier than expected. Ten minutes later, the cries from his eighteen-month-old brother can be heard coming from the



Little Man indulges his fascination for buses.



A gorilla statue watches over Little Man and his sister.

top of the stairs. This little fella knows all too well what it's like to be woken by his big brother's angry blow-ups.

Little Man isn't able to see the reasons behind my refusal. In his eyes, he's hungry and that's that. I'm the evil mother he angrily claims is starving her child. This rigid thinking disallows me any way to reason with him. He begs, pleads, shouts and curses until he has nothing left to give. Out of tears and breath, red-eyed and flushed, he finally falls asleep after 5am slumped over the washing basket.

I, like him, feel drained and exhausted. Yet I cannot sleep because if I do, no one will receive an education. Instead of gaining the support I crave, I will instead face a school attendance order, undoubtedly leading to prosecution. Oh yes, I've been there before.

Being a parent to a child on the spectrum isn't the easiest job in the world; however, it's not the worst either.

Despite the late nights, meltdowns, constant exclusions from school and daily bursts of anxiety, it's an incredibly rewarding experience. My son can be a joy, overly polite, funny, interesting and, although he wouldn't agree, intelligent in an array of areas.

Many people struggle to accept my child's diagnosis, simply branding him a menace

I often sit and watch him engage in play. At first sight, it may seem strange if you didn't know him, a child beeping like a bus while holding a kitchen utensil in front of his face and a pencil behind his back (so to create a front and a back to his virtual bus), while recalling hundreds of bus destinations from memory. For

me, it's a beautiful sight, and something that I hold on to as tightly as I can, because this is when he is truly relaxed and blissfully happy. This is what every mother wants to see from her child.

What makes life that bit more difficult is the fact that my son looks like a typical ten-year-old boy. There are days when I, myself, wonder: "Did they get it wrong?" Then something happens, an unexpected change, a sensory related trigger, a late bus or a sudden amendment to the TV listings, and I see it. I see that, yes, my little boy is different.

It's sad but true that many people struggle to accept my child's diagnosis, simply branding him a menace. I know what people say: "It's an excuse for bad behaviour", "we didn't have it in our day", "it's the way he's brought up" or "I blame the parents"!

He's a child who, of course, has the natural propensity to misbehave; after all, he is a boy of ten. But it hurts even more when those closest to you fail to accept his uniqueness. I don't blame them, though, or at least I try not to, but it is clear that those who have daily contact with him are better able to see his Asperger's. Strangers may even notice something different and show some understanding when he patrols the bus demanding that feet be removed from the seats and litter picked up from the floor. Maybe they notice something when he suddenly dashes off to ring the bell for them as they approach their destination or when he tries to engage them in his one-way conversation on the topic of bus manufacturers. However, when it comes to him cursing and kicking shop displays in the local supermarket, many fail to understand!

As a family, we are often the subject of a lot of attention, normally for the wrong reasons. I'm used to the deadly

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stares from my fellow shoppers, the whispers from the mothers at the school gate, the constant phone calls from a disapproving headteacher or the parent who hurriedly removes her child from the park just because my child is playing there too. It happens every day, but it hurts just the same.

I have done my fair share of fighting for my child. We've battled for the statement, and then battled for that statement to be amended. We've been through a discrimination case and a long fight to secure the right school placement for Little Man, a special school that meets his complex needs. I have watched my child be excluded from everything he loves and hidden away like some dangerous wild animal. I have seen him taught in isolation and I have seen him so confused by others behaviour towards him that he has banged his own head against a wall while scratching his arm until it bleeds.

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How many mothers have had to watch their young child lose all their self esteem while asking the simple question: "Mum, why can't I just be normal?"

Thankfully, we are in a better place these days, and my son has just started at his new independent special school for children on the autism spectrum. After just one morning at the school, I noted a change. I saw a smiling, happy boy who told me: "I made a friend today. He has Asperger's too."

Life can present everyone with new challenges and rewards every single

day. When your child has Asperger's, those challenges tend to be a little more complex, while the rewards can be all the more satisfying. The little things that you take for granted, such as your child being able to happily mix among his peers, or engage in the simple task of teeth brushing, are daily struggles and achievements for us.

There is much more to understanding Asperger's than can be found watching a re-run of Rainman, and it is important to remember that sometimes a bus really isn't just a bus. If being a parent to a child with autism and SEN has taught me anything, it is that the SEN system is something of a jungle; it is not unusual to meet with your child's senior teaching team more than you do with your own friends.

Parenting any child is a huge learning experience, but parenting a child on the autistic spectrum takes this learning experience to a whole new level. I have learnt more about myself than I ever thought possible. Along the way, I have tried to embrace the awesome nature of my son and his situation, rather than simply wondering what things might have been like if he were different. I'm not looking for a miracle cure, or even a sympathetic smile; all I ask is for a little understanding.

The next time you hear a child, branding his mother some awful name while kicking over cans of baked beans in the supermarket, please think twice before judging him. After all, that could well be my child, my Little Man. **SEN**



A quiet moment for brother and sister.

Further information

Claire Louise Parkinson publishes a blog, *A Boy with Asperger's*, at: aspergersinfo.wordpress.com