



# James

James was a lively toddler with an inquisitive nature, though his family recognised early on that some of his behaviours weren't typical for a boy of his age. He managed to attend school up until year 3 at which point James' anxiety levels became very apparent, and his negative feelings about school intensified following episodes of restraint. James' Mum recognised similarities between his presentation and the children diagnosed with a PDA profile on the Channel 4 programme 'Born Naughty', and James was eventually diagnosed with ASD and co-occurring anxiety. His family have worked hard to support him and provide the best environment for him to be able to continue his education at home.

When I reflect on life with James as a baby I can now better understand the challenges we faced. He was difficult to settle and never managed to sleep through the night. I breastfed him and he would suckle for lengthy periods of time, which I now recognise as him trying to meet his sensory needs. When I carried him it needed to be in a precise way and if I got it wrong we would have to begin again. We could be caught in this loop for hours and his distress was beyond any other type of distress he had shown.

I usually ended up staying with James at nursery or playgroup sessions because he became too upset when I left him. He found adjusting to transitions very difficult and would protest by screaming, throwing or getting naked. His 'temper tantrums', as we considered them then, could last for hours. Many developmental milestones were met at appropriate ages although there were variations such as his unique backwards crawling style.

As he developed into a hyperactive toddler, it became obvious that he had no real sense of consequence or pain. He once had a nosebleed after he ran head first into a wall because he had been experimenting with throwing himself against it. James was an inquisitive youngster; he would break things to investigate them rather than out of naughtiness.

James managed to attend mainstream school up until Key Stage 2. During these early years he displayed high levels of anxiety, which escalated further once he entered Key Stage 3. He didn't have any formal diagnosis but I did suggest early on to the school that he might have ASD. I have an older child with Asperger's so I considered an autism diagnosis for James quite quickly once things started to deteriorate. Although I felt he didn't quite fit the profile of Asperger's, I identified many character traits which were similar.

James was accepted onto the CAMHS waiting list for assessment in Year 3. During this period a series of events triggered an episode of extreme anxiety at school. He was restrained during a meltdown which left him feeling deeply traumatised. This experience resulted in James beginning a period of 'life refusal'. His anxiety was so severe that he felt unable to attend school and refused to leave the house, even to visit his Dad. He was experiencing up to three meltdowns a day.

I was frequently blamed for the behaviour James displayed and was told repeatedly that my parenting style wasn't firm enough. I knew this wasn't the case and my son was actually suffering as a result of his negative experience at school where his sensory needs were not met. Traditional reward and consequence based discipline didn't work with James and only caused his anxiety to further increase. I struggled to get the school to support my opinion that he could have ASD.

I decided to home educate James after our relationship with the school had broken down completely. I applied for an EHCP while beginning to explore other educational options. For about a year I tried to find him an alternative placement, but we were in an impossible situation as without an official diagnosis he couldn't access specialist autism placements.

I first became aware of PDA following the Channel 4 documentary 'Born Naughty'. The profiles of the children featured struck a chord and I felt that James displayed many similar behaviours. I realised that, for him, anxiety underpins everything and that avoidance was a form of self-protection.

We waited 2 years before finally undergoing an ADOS assessment with CAMHS. A conclusive diagnosis was not reached. The assessment process relied heavily on observations made by members of school staff who had limited experience in recognising autism. Subtle signs of anxiety displayed by James had not been noted, due to his sophisticated ability to mask his feelings. I recall speaking to a senior psychologist at CAMHS prior to assessment and was told PDA wasn't recognised in the Leeds area. I decided to pursue a private diagnosis and consulted both an educational psychologist and a psychiatrist. The result from them both was a clear affirmation that James fitted the PDA profile. His official diagnosis is ASD with co-occurring anxiety.

After receiving the diagnosis of ASD, we were able to access CAMHS and began working with them to address my son's anxiety issues. Interestingly the case-holder described James as having 'entrenched demand avoidance'. We discussed whether this fitted their understanding of the PDA profile and they commented that he had been 'too compliant during their ADOS assessment'. This discrepancy in opinions highlights the challenges

we have faced. James presents with a PDA profile, but because of where we live there isn't the diagnostic pathway available to officially recognise it.

CAMHS prescribed CBT strategies to help James, but unfortunately these had a detrimental effect on his mental health. Graduated exposure was advised which involved changing tiny aspects of his life over a period of time. Unfortunately these small changes triggered severe anxiety and a crisis point was reached. Following episodes of suicidal ideation and occasions of police restraint, James needed a brief section under the mental health act. This was deeply distressing for us all and shouldn't have happened. James was taken by the police to a psychiatric hospital during a meltdown at home. Neighbours had called them out and I was forced to let them in. I objected to his removal and restraint as it was only causing him more distress. After 2 hours he was released back into my care, but James has endured ongoing trauma as a result of this and it has increased his anxieties about being restrained at school. I am still in discussion with CAMHS as to the best way to manage his anxiety. My request for CCG funding to gain access to a psychologist at the Elizabeth Newson Centre has been unsuccessful.

Following his ASD diagnosis, James was placed on the register at a local autism hub but he still finds it difficult to attend due to his high level of school-related anxiety. I educate him at home because I can fully meet his sensory needs - a teacher also visits him for 1.5 hours per week. I have requested a personal budget to cover the costs involved, but am still waiting to find out whether this will be authorised. James requires a bespoke, creative and flexible educational package. After 4 years of my advocacy on his behalf, professionals are beginning to agree with me that this is the way forward.

As a family we now have increased empathy for James. Controversially to some, I try and give my son as much autonomy and control of his life as possible. We have a set of non-negotiable boundaries (for which I faced meltdowns when establishing) around bedtime, mealtimes, hygiene and learning. I try to negotiate with him as much as possible. If a meltdown occurs I let it run its natural course. I try to intervene when he is becoming overstimulated or during difficult times of the day such as getting out of the bath. Distraction techniques work and tactics I employ include quizzes, top 5 stats and telling jokes about his current special interest. I employ natural consequences when items get broken during a meltdown, for instance I have delayed purchasing a replacement for our damaged X-box. I don't punish him or use reward systems. During difficult times I remind myself that James is trying to control his own anxiety and it must be extremely distressing for him. He isn't trying to control me but merely reorder his immediate environment back to within his comfort zone.

Since embarking on this journey with James I have become a more accepting and tolerant parent. I am happy to go at my son's pace and get less frustrated when things don't happen such as trips out. Since being more relaxed and less 'pushy', my son's overall anxiety has lessened and we actually end up achieving more.

James is a very loving young man. He has much compassion and empathy for animals and is full of respect and kindness for them. He is physically gifted and an accomplished gymnast having taught himself front flips. He also has an amazing amount of stamina.

My son is a born negotiator and doesn't obey the usual rules of hierarchy when interacting with people. This makes for a formidable combination of characteristics and he has successfully lowered the purchase price of many things for me! He has incredible attention to detail and is a fast-paced thinker which often helps me avoid making mistakes. James has a great sense of humour and regularly makes me laugh and smile. I haven't been able to beat him at chess in a very long time as he is such a brilliant, strategic thinker.