

John

Through her own research, John's Mum felt he had many autistic traits but that there were boxes he didn't fit. John struggled on with a non-specific autism diagnosis but school attendance was erratic and recommended strategies made him worse. After a lengthy battle and multiple diagnoses, John was eventually given a PDA diagnosis aged 12. In just a year, the difference this differentiated diagnosis has made has been nothing short of amazing.

I wasn't looking for any kind of diagnosis as such to start off with, I just wanted to know what was wrong with my little boy so that I could help him. John didn't voluntarily speak with his class teacher for his entire first year at school, and would spend the day on a computer facing a wall at the back of the classroom. Whilst in some ways he was a model pupil and followed all the rules, he would cry when he came out of school and worry about all sorts of things a 4 year old shouldn't, for instance he worried that we'd die and he wouldn't know who would look after him.

So I went to see our GP who referred us to CAMHS. School also asked an educational psychologist to look at John. The CAMHS conclusion was that he was extremely shy and selectively mute and that these two issues were causing his severe anxiety. I totally disagreed and raised my concerns, but was met by a completely dismissive attitude. By this point I had been reading up myself and felt that John had many traits of autism, but there were also boxes that he didn't seem to fit. I returned to the GP who referred us to a paediatrician who was very supportive but unfortunately retired before he was able to request an out of area referral, and we were referred back to CAMHS.

After a reasonably calm Year 2 at school, Year 3 was a different story - things were escalating at school with multiple exclusions and his behaviour was deteriorating at home, so we gave CAMHS another try. We were met with lengthy delays and reluctance to alter their original diagnosis, until the day I called in complete distress because John aged only 8 had started self-harming. He was assessed by two clinicians who agreed to an autism assessment but the waiting list was 10 months. I complained to the Chief Executive of our Primary Care Trust and asked my GP to do likewise. CAMHS then agreed to see John on an emergency appointment in 5-6 weeks. Alongside all this I had requested a statement of educational needs. As part of this process we saw another paediatrician who really took ownership of our case and secured an out of area referral for us. [Aged 9, John was diagnosed with autism.](#)

[We managed with that diagnosis for a while, but his schooling was erratic and behavioural experts had no idea how to manage him with their strategies only serving to make him worse.](#) My cousin who manages a nursery first mentioned PDA to me – at that time there wasn't much information available and all I could find was a paper written by Elizabeth Newson. It was as if she had met and written about John! I felt it was essential to revise his diagnosis and embarked on a lengthy battle with our Clinical Commissioning Group. Finally I decided that I just had to take matters into my own hands because John was struggling so much, so I paid privately for an assessment at the Elizabeth Newson Centre. [Aged 12, John was diagnosed with PDA.](#)

[John has only had the correct diagnosis for just over a year and the difference is amazing.](#) His diagnosis meant that he could attend a National Autistic Society school where his behaviours are well understood and accommodated. The school is fantastic, allowing him genuine choices, flexibility, plenty of processing time and treating him more like an adult than a child. This means he can access an education he couldn't have done before due to his anxiety being so high. PDA strategies enable John to communicate, learn, stay in control and reduce his stress levels. John is highly intelligent and has always understood that he struggles with life. By the time he was six he was asking what was wrong with his brain and why it didn't work properly. [I think it's the stress of trying to be 'normal' that used to cause the severe meltdowns after school.](#) Life is also now much improved at home – we've learned to keep home a demand-free zone which keeps anxiety to a minimum and has all but eliminated meltdowns.

It has been such a long, hard battle but I am so relieved that we got there in the end. I truly believe that without a properly differentiated diagnosis of PDA John would have been lost – to himself, to me and to the world at large.