



# Dan

*Because Dan masked his difficulties at school, whilst his anxiety was sky high at home and it was a daily battle to get him to attend, it was only when he ran from school that we were taken seriously. Despite school & external agencies working hard, their efforts were targeted at the incorrect diagnosis of Asperger's and so failed. Eventually PDA was incorporated into his diagnosis and things have really turned around since joining a mainstream senior school with a specialist ASD unit. It's been such an enormous relief that Dan is now properly understood and supported. PDA means that you need to completely change your ideas about how to parent!*

Looking back, I realise my first concerns about Dan arose when he attended pre-school, he was never really happy to be left and didn't enjoy it. I remember them saying 'If only he'd realise that we're having fun he'd be fine!'

The first couple of years at school seemed to go OK but major issues started in Year 2 when his teacher was particularly severe and Dan became extremely anxious. I spoke to my GP about my concerns and after speaking with my son's school I was initially dismissed as just being a fussy Mum. *Dan masked his difficulties at school and so kept under the radar, but at home his anxiety about school was sky high and it was a daily battle to try and get him to attend.*

Year 3 was fairly straightforward, with a really laid back male teacher who just seemed to have a knack of saying and doing the right thing. However in Year 4 Dan imploded completely and was freaked out by his new teacher who was very unconventional. I offered to stay at school with him until he was settled, and had thought initially that this would just be for 1/2 an hour or so a day maybe for a few months. Little did I know! I often stayed for 3 hours and this went on for 18 months!

At this point we took Dan to a private psychologist to try and help him with his anxiety. After completing four sessions the recommendation was that we should take Dan for an autism assessment. Around this time Dan escaped from school for the first time - it was only then that school began to take things seriously and they contacted CAMHS. Astonishingly we were seen in just three weeks, which I think was because of him school refusing. He was accepted for counselling at CAMHS and they acknowledged that he had autistic traits but said that it would take 3 years for him to be seen for an autism assessment. We went privately to a diagnostic centre in Cheshire and at age 9 Dan was diagnosed with Asperger's and anxiety disorder. At this point we also secured a statement of educational needs for him.

I first came across PDA on an autism parents' forum online and looked into it further. The first thing that rang bells for me on reading about PDA was something that school had said – some tactic or technique they would use to get him into the classroom would work once but not a second time because he would figure it out and not fall for it again. We mentioned PDA to the private psychiatrist who diagnosed Dan but he felt PDA was a fad that wouldn't ever be accepted as a separate diagnosis and so we didn't pursue it at that juncture.

Dan's school tried hard and had lots of help from external agencies, but this failed because all the interventions were being focussed on what would work for someone with Asperger's. For instance, the recommendation for an Asperger's child might be to have a visual timetable whereas it can work better for Dan to keep things flexible and introduce them 'at the right moment'; or keeping instructions very clear and simple whereas it's actually more effective to weave a story or use humour to introduce something and tempt him to join in. When these didn't work Dan was described as being manipulative and being so clever that he could 'see through his autism and use it to his advantage'. Also everyone's main priority seemed to be about school attendance – at one point it was even suggested that a fake letter from the police be sent to our son saying that if he didn't attend his parents would be jailed! We found this really quite shocking, and were not willing to go down the line of terrifying our child into attending school.

Dan was medically signed off school by his CAMHS psychiatrist because of his anxiety and spent most of Year 6 out of school. We managed to secure medical needs tutoring, initially just for the legal minimum of 6 hours per week but eventually for 10 hours, which worked out well with a great tutor who allowed Dan to lead the content and nature of the lessons so that he participated willingly.

PDA next came up when I attended a course for the parents' of children recently diagnosed with an ASD at CAMHS. The trainer was fully aware of PDA and accepted it as distinct condition. I shared some information with her about my son and showed her a video of how he acted after school (talking non-stop and using unusual voices) and on the back of this she recommended that we seek a revised diagnosis.

I completed a long form which I found on the PDA Resource website and sent it to the CAMHS psychiatrist Dan was seeing. He then wrote a letter to school confirming that Dan 'has features of PDA in addition to his Autism Spectrum Condition' and that there were specific handling strategies and educational guidelines that should be used for him. Because of this letter we were able to get PDA included in his statement, and I found a list of strategies online which I got incorporated.

Things turned around for us at senior school. I knew we'd found the right placement for Dan when I was looking round a large mainstream secondary school with an attached autism unit. I hadn't even mentioned PDA in relation to my son but on chatting with the person showing me round they instantly said 'oh, he sounds very PDA' in a completely casual and relaxed way. When I raised concerns such as 'what will happen if he doesn't get in the taxi?' I was told 'don't worry about it, we'll deal with it'. They said they would need additional funding over and above the usual funding for an autistic child, but I heard nothing further about it because they just took care of it completely. **It was such an enormous relief that someone else took ownership of things - at primary school I had felt it was all my responsibility and been left with the impression that my son was un-educatable!**

On starting secondary school, Dan attended for a few days and then refused. **The Autism team handled this superbly.** Everything was presented as if it was entirely his choice. Initially they backed off completely, then after a few days his keyworker emailed him casually with a chatty message sharing a new story linked to his area of interest. He happily replied and after a few exchanges they gently introduced a few things about school, fun things that were happening that he might want to get involved with. After a few more days Dan announced off his own bat that he thought he'd go to school today.

During Year 7 he managed around half a timetable and there were times when he might only attend around 30% of lessons. The Autism team would get the work and see if he'd do it in the unit. They also removed the need to do homework completely, and this made a huge difference. Now in Year 8 he's managing a virtually full timetable.

They've changed his keyworker twice – they say this is a common requirement with PDA because of the need to keep coming up with new strategies and needing breathing space from each other. But nothing is ever taken anything personally, each day is a fresh start and there is no pressure over relationships and they just rejig things if he seems to fall out with people. Similarly if Dan doesn't get along with a particular teacher they move him to different classes, which is one advantage of being in a large mainstream school as they have alternative options. Although over time they are trying to resolve things instead of moving him so that he can see that things can get better and move on. They have regular chats to go over what has happened or what's coming up. Dan now approaches them proactively to discuss things. He also has Speech & Language Therapy at school – this focusses on emotions and he has found it very helpful.

All the pressure has been taken us as off parents as it's made the world of difference. But along the way **we've had to totally change our idea of how to parent.** Because he is managing to attend school we make virtually no demands at home. This means he does hardly anything other than what he wants to do. This can be frustrating at times and impacts his younger sibling (who is fortunately very laid back and supportive of his brother) but **as soon as we put any pressure on he starts to shut down, so we prioritise.** Holidays can be tricky as Dan refuses to go on a plane or through the tunnel, but he willingly stays with a grandparent so the rest of the family can go.

I feel that PDA is more of a hidden disability because of the sociability aspect – they can mimic and fit in up to a point. He can cope with some changes, likes novelty, variety and surprises (but not different light shades – I changed these and he refused to turn the lights on for 6 months!). Some of the mainstream staff at school struggle

to believe there's anything wrong as when Dan is on form no one would know a thing, but then they're surprised when things go awry. Luckily he also has a good group of friends.

Dan has been [medicated for his anxiety since year 5 \(he takes fluoxetine\)](#) and he has [melatonin to help with sleep](#). One thing we noticed was that when he started on his anxiety medication and some of his anxieties were suppressed, his autistic traits (such as literal understanding) stood out much more but we hadn't noticed them so much when he was overwhelmed by his anxieties. We recently tried to stop the medication as things were going so well, but his old anxieties returned immediately and he ran to the unit in distress wanting to go home so he went back on it.

[A differentiated diagnosis was so important to us as it meant that the correct strategies could be used](#). If Dan had gone to a mainstream senior school with a diagnosis of Asperger's it would have failed and he'd be out of school. We needed somewhere with a specialist ability to deal with PDA. I am concerned for the future because I know things are only working now because of the good support he's currently getting, but the current provision will stop at 16.

My top tip is to be completely flexible and not to expect anything to work/happen again just because it has once. Also [be on the side of your child – we were so pressured to try and make him do things and really had to take a step back at times and ensure we were putting Dan first](#). People struggle to understand PDA because it's so hidden and subtle. On the surface is a child who seems OK but underneath they're not coping.