

# Katie

*Children like Katie seem too complicated for the usual system, no one knows what to do with them. This puts all the pressure on the parents. And yet my evidence and strong belief that Katie had PDA were dismissed and my parenting blamed. Advice targeting the incorrect diagnosis of ADHD was not only unhelpful but actually damaging. A change in school leadership and attitude led to a dramatic downturn in events. But since then, using the correct strategies has resulted in a popular child who can navigate school with increasing confidence.*

School life was difficult for Katie from the outset, with her first exclusion at the tender age of 3. Whilst she was given 1:1 support without having had any formal diagnosis, we knew that she would need lots of understanding and support to get through mainstream education so we began the process of pursuing a diagnosis.

The initial referral came with the support of our health visitor, but still it took months for any response from CAMHS and then we were ping-ponged between CAMHS and the paediatrician with each saying the other should take responsibility for Katie. We were caught up in various rounds of 'restructuring' which caused further delay and confusion. During this time Katie's behaviours worsened despite all my efforts. She was eventually diagnosed with ADHD aged 5. I had discovered PDA the previous year, having spent hours on end trawling the Internet. I experienced the classic lightbulb moment when I found a description of PDA on the National Autistic Society website – here was an accurate description of my daughter and a clear explanation for her behaviour!

I strongly disagreed with the ADHD diagnosis so sought a second opinion. Sadly, whilst I thought I was accessing a second opinion from an independent clinician, the two were connected and they reached the same conclusion despite my dissatisfaction. [Although I provided lots of evidence to support my belief that Katie had PDA, this was dismissed.](#) I believe that this was because the diagnosing clinician didn't have sufficient understanding of PDA nor of how autism presents in girls.

We found the CAMHS advice, targeting the incorrect diagnosis of ADHD, to be not only totally unhelpful but actually damaging both at home and at school. For instance, implementing routines/rewards/consequences just added to Katie's distress, she seems to live in the here and now and working towards a reward seems to signpost her failure to have achieved, demotivating her and impacting her self-esteem. So instead we all followed advice aimed at PDA children which was much more effective.

Things progressed relatively smoothly for the next couple of years with everyone making progress using PDA-related guidance. Katie's school was very supportive, with staff genuinely embracing her charismatic personality. However, changes in the school leadership team led to a downturn in events. A new temporary head teacher decided that Katie was 'just naughty' and simply needed discipline. This new head seemed to really pick on Katie, inventing new rules which seemed designed to punish her, preventing her from having her TA in the classroom, keeping her inside at playtime, even physically dragging her from the classroom on one occasion, and excluded her several times.

Katie's behaviour escalated at school to the degree that during one meltdown she attacked several members of staff and pulled a toilet door off its hinges. On the days she managed to cope at school, by home time she was ready to explode and behaviour at home plummeted. Kicking, hitting, biting, screaming, throwing things, slamming doors ... resulting in holes in walls and umpteen broken items despite our well-established routine of Katie retreating to her safe space whenever she was not coping. One time she threatened to jump out of a third floor window and when I intervened I was met by a full force punch on my nose, though seeing me burst into tears seemed to snap her out of her rage. After this she ran from the house twice and because we were so distressed about the effect this was having we went to see our GP who was very supportive and signed Katie off school for the remainder of the summer term.

Fortunately a new head teacher arrived in the September - but I had realised how badly we needed an accurate diagnosis. With the support of the CAMHS psychiatrist Katie was referred back to the centre from which I had sought a second opinion when given her ADHD diagnosis. They now felt her autistic traits were more pronounced and she was diagnosed as having an Autistic Spectrum Disorder at 9. PDA was not included in her diagnosis, despite the fact we have made good progress with PDA strategies for 5 years.

The ADHD diagnosis came with a recommendation for medication, which we resisted for several years. I asked for dietary or other recommendations, only to be told that if we didn't medicate CAMHS wouldn't offer any further support! Eventually we relented and on the advice of her CAMHS psychiatrist who I trusted (and who, incidentally, identified traits of PDA within 20 minutes of observing Katie!) tried methylphenidate. This helped to improve things academically, but it gave her head aches, she lost her healthy appetite and it had no impact on her aggressive personality. After a few months we trialled risperidone, which helped from the outset. It seemed to give her that extra second's thinking time which makes all the difference. The day after she started on risperidone her younger brother took her pens, an incident which would normally provoke a major outburst, but she said simply 'Those are mine, here these are yours!'. That simple exchange was totally ground breaking for us! Whilst we still feel like we're walking on egg shells, it's not nearly like living with the Jekyll & Hyde character she was before was on medication. With Katie's agreement we also started a restricted diet 18 months ago – this has had a very beneficial impact by reducing her sensory difficulties thus enabling her to function better in and out of school.

It strikes me that children like Katie are 'too complicated' for the usual system and no one really knows what to do with them. This puts all the pressure onto the parents. Whilst autism was first mentioned as a possibility when my daughter was 3, her superficial abilities and amazing acting skills has always confused professionals.

Katie is aware of and has embraced her autism diagnosis – it has helped her to feel that she isn't alone in her struggles. I've also found it helps because people are more understanding when I can explain her autism and extreme anxiety. She loves being with other children and they with her, though school remains hard. After our dreadful experience with the awful head teacher we seriously considered home schooling and Katie knows that she can choose this option at any time, however she's opting to stay in school. We've really benefited from having good one to one support, including 6 years with the same amazing teaching assistant.

School strategies that work for Katie include: having familiar, trusted staff present at all times; starting each day anew with no consequences for behaviour; having a safe space to retreat to; consistent seating arrangements so that she doesn't have to navigate the chaos of free seating; using calm voices at all times; avoiding over-preparation as she needs less rehearsal than most and it avoids her anxiety building; flexible uniform policy; optional homework. Katie has simple strategies – kind hands, kind feet, kind words, tell an adult - which seem to cover most eventualities. If an incident occurs we all look at what happened and why and what can be done to prevent a recurrence.

I feel hopeful for the future. Katie is a confident and articulate child now who is much better able to identify her emotions and use strategies such as her safe space when overwhelmed. I am such a better parent and person for having a child with PDA, I am calmer and more open to letting my children lead the way. My youngest child, who is neuro-typical, benefits from this calmer parenting too.