



# Agnes

During her early years at school Agnes was a model pupil - in stark contrast to the behaviour she displayed at home. Her parents and siblings struggled to understand where her outbursts of anger stemmed from. Over time Agnes's school related anxiety increased until she began a period of complete school refusal. Her family worked hard to regain her trust and provide her with the support she required to allow her to resume her education.

Agnes was in Year 2 when we first sought private professional advice to help us deal with her worrying behaviour. Maintaining a happy family life had become impossible as we tried to cope with her angry outbursts, which were often accompanied by physical violence. The [psychologist was adamant that she wasn't autistic](#), instead insisting her difficulties stemmed from dealing with the arrival of her brother and sister when she was a young child. It was true that Agnes often voiced her displeasure at having siblings, but this explanation still seemed incongruous to us. We found Agnes's behaviour became increasingly challenging despite the fact that her home life had remained consistent, loving and stable.

Agnes attended a mainstream primary school and [throughout reception and Year 1 she was described as a 'model student'](#). As she progressed through Year 2, Agnes's anxiety levels increased. We struggled to understand what was at the root of her difficulties. Agnes would get frustrated and hit us or throw objects and even punch holes in the wall. There were occasional days when her anxiety was so extreme that she refused to attend school.

Fast forward to Year 5 and Agnes's school refusal was becoming more frequent. She didn't actually miss a day thanks to a determined, patient teaching assistant who managed to persuade her to go in. Her reluctance to attend was fuelled partly by a personality clash with her teacher. Agnes has a strong sense of justice and felt the teacher had not dealt with a group of disruptive boys appropriately. Similarly when Agnes was subjected to a period of bullying, she felt unsupported by the teacher. This further intensified her negative feelings about school.

At our request in Year 6, Agnes received some input from CAMHS and had a series of 1:1 sessions with a counsellor. She did seem happier during this period, but once she had completed the sessions things deteriorated again. In hindsight, we realised that it wasn't

so much the content of these sessions that aided Agnes but the delivery in a 1:1 setting that she enjoyed. We continued to find her behaviour bewildering and struggled to understand what was causing her so much distress and anger.

Things didn't improve once Agnes started secondary school. During Year 7 we approached the school to request support for her and they couldn't equate the high achieving, model pupil they saw with the anxious, aggressive child we experienced at home. [Agnes has never had a meltdown at school.](#)

During this time we received some support from Social Care in the form of parenting classes based on the Triple-P Positive Parenting Programme. The programme looks at ways to deal with behaviour through the use of rewards and consequences. We tried many of the strategies and techniques recommended by the programme but had limited success. With hindsight, [the PPP strategies actually exacerbated many of Agnes's underlying demand-avoidance and control-related anxieties](#), leading to ongoing difficulties with Agnes's relationship with her father.

Daily battles to get Agnes to school had taken their toll on me and throughout Year 8 her attendance started to wane as I wasn't physically able to get her to school. My mental health was suffering so we tried an alternative approach. For a period of a few weeks, my husband took over the responsibility of getting her to school. His approach was strict and heavy handed (this was before we had a diagnosis and before we realised that her anxiety is often not about anything specific). Unfortunately this further damaged Agnes's trust in her father and it has since taken 3 years of hard work for him to regain her confidence and repair their relationship. Up until very recently, Agnes would remind him of 'when I was in Year 8' as a means of avoiding any demands he placed on her. We have both apologised many times for how we handled things around this time. My husband has become involved in a Facebook group that supports men experiencing violent behaviour from their children. He has also made huge efforts to educate himself about PDA. This seems to have proved to Agnes that he takes her difficulties seriously and is dedicated to supporting her in the future.

I was first made aware of PDA via an online support forum. A mother was experiencing similar challenges with her daughter and shared her knowledge of PDA with me. I googled The PDA Society and it was as if a light went on: a very big 'eureka' moment. We [began to appreciate how Agnes's fear of being out of control had sparked historical episodes of violence within our home.](#) Agnes needs to feel in control of not only her own life but other peoples' lives too, which has had an impact on the wellbeing of her siblings and parents. When her anxiety is particularly acute she will almost obsessively micromanage activities in the home, all the while meticulously avoiding any attempts to assume any accountability on her part, which can be utterly exhausting.

We approached CAMHS again during autumn 2015 as Agnes moved into Year 8. This time they acknowledged our concerns about her behaviour and took her family history into consideration, as Agnes has a cousin with HFA (High Functioning Autism). They agreed to assess her for ASD the following summer. We felt it was unlikely PDA would be included in her diagnosis as it wasn't recognised by the professionals we dealt with. Agnes was diagnosed with HFA when she was 13, just as she commenced Year 9.

A meeting with the school was held to discuss general ASD friendly strategies they could use to support her. Unfortunately their good intentions were short-lived. Our meeting was held in the morning and it had been agreed that, should she require it, Agnes was allowed out of the classroom at any time for some cooling off, quiet time. That afternoon Agnes took a much-needed break and after only 15 minutes staff members tried to force her back into the classroom. They irrevocably broke any residue of trust Agnes had in them. From the October half term in Year 9, Agnes stopped attending school.

We started the process of applying for an EHCP so that we could access alternative school settings for Agnes. At the time we were considering a mainstream school with an ARP (Autism Resourced Provision) unit where the staff had undergone further training in PDA. Whilst PDA isn't mentioned in her diagnosis, we knew that it was crucial she attended a placement that understood PDA-friendly teaching methods. We couldn't access this placement because Agnes's school wouldn't support our EHCP application stating she 'didn't need 1:1 support'. I disputed this and the process began in January 2017.

In March 2017 we were informed that our application wouldn't progress as the County Council insisted her needs could be met in school. We attended a 'Way Forward' meeting with Council representatives which allowed us the opportunity to give a full account of the situation. Agnes's school hadn't been very forthcoming with information regarding her true attendance and the strategies they had already tried. Following the meeting, the County Council agreed they would assess Agnes and school agreed to take the lead on this. Unfortunately there were numerous delays in processing the paperwork by the school and the assessment didn't begin until the summer term 2017.

To aid Agnes's transition back to education, she attended short sessions in the CAMHS school room. Following this it was decided that a UTC (University Technical College) might provide a long term solution as although still a mainstream setting it has a much smaller cohort. Agnes was enrolled from September to November 2017. The staff weren't as experienced with ASD friendly teaching as we had been led to believe, meaning Agnes didn't receive the full support she needed. The UTC did provide more information for the EHCP assessment and we were issued with a draft EHCP in February 2018.

In total Agnes missed 17 months of school and received 80 hours of schooling in the CAMHS classroom or with the 1:1 tutor. We were clear that in order to continue with her education Agnes needed a specialist setting. I visited the nearest suitable schools which were all out of county. With Agnes's approval she began her current placement in June 2018 just as she was nearing the end of Year 10. Agnes's school is an Independent ASD Specialist School and is amazing. She is still transitioning to full time. There are only 70 children in the school and many of them have the same issues as her. The school know how to encourage her without pressuring and she has made a friend!

We have instinctively reduced demands placed on Agnes at home and since learning about PDA we understand why these techniques have made such a difference. Mealtimes in our house have always been ad hoc affairs, meaning Agnes can choose whether she joins us to eat or not. We do try to sit down for Sunday lunch together and sometimes this leads to a family games session. Things have improved since Agnes has

been capable of describing her feelings more clearly and explaining why she finds certain situations difficult. Many people with ASD thrive with routine, stability and repetition. To some extent this applies to Agnes, but a routine in itself can feel like a demand to her so we have become very creative about how we introduce them.

My involvement with local PDA groups has provided an invaluable source of support to both Agnes and our family. I met a fantastic friend through one group who has a daughter 18 months younger than Agnes with very similar difficulties. The girls identify with one another and can share their experiences. Agnes has come to realise that there are other people who struggle just as much as she does. My friend and I offer each other emotional support and practical help that only people in similar circumstances can provide.

Post-diagnostic support from CAMHS has been variable. Immediately after diagnosis we received two group sessions with a nurse practitioner and were discharged. Agnes's autism fuels her anxiety, which in turn appears to depress her mood. She is academically very able and worries that her patchy school attendance means she is falling behind her peers. Agnes was referred to a CAMHS psychiatrist for her depression and anxiety and was prescribed a number of different medications (with mixed results) but has finally found a regimen that helps her manage her mood and anxiety more effectively.

Agnes has a greater understanding of herself now and accepts that she is normal but with additional challenges. She feels less overwhelmed, which in turn has led to fewer episodes of violent behaviour. Whereas previously we have needed the police to assist us and calm Agnes down, now situations don't escalate to that level.

We look forward to Agnes becoming an independent young woman. She's starting to think about the future which is amazing and something we couldn't have imagined even 6 months ago. Agnes is passionate about many things with a specific interest in politics. She feels strongly that other children shouldn't be failed by the education system in the way she was. I pity the organisations that come up against her campaigning might!

To anyone in a similar position to us I advise them to trust their instincts, research and don't take 'no' for an answer. Remember that autism in girls can present very differently to boys and although they may appear to be coping their struggles are real.