



Milly

After years of increasingly challenging behaviour, an inaccurate Asperger's diagnosis and no professional support, my family was in complete crisis. Only through my own tenacity, the support of fellow parents and consistent use of PDA strategies have we been able to see the light at the end of the tunnel. Milly's demand avoidance hasn't gone away, but by finely tuning the adjustments and adaptations she needs, daily life has been largely transformed. The way PDA impacts Milly has changed over time – now a teenager, she has increasing self-awareness and is developing her own coping strategies, but she is crippled by the internal conflict of trying to comply with her own demands and wishes.

Difficulties began to emerge when my daughter was approximately 18 months old. We thought that it was the terrible twos and expected it to pass in due course but unfortunately this behaviour, which at the time just seemed wilful and oppositional, continued and spread into every area of daily life.

Things really escalated when she began nursery school at our local primary school. By the age of only four years old we were experiencing multiple school exclusions, including illegally imposed exclusions. Her teachers claimed that they had never experienced a child like this before because nothing worked, no matter how consistent both home and the school were with traditional behaviour strategies such as rewards, consequences, star charts, praising good behaviour and ignoring the bad.

At the school's request we sought help and advice from Health, but we simply became stuck in the CAMHS hamster wheel going around in circles getting nowhere fast. "Triple P" parenting and repeated emphasis on traditional behaviour strategies that had proved ineffective time and time again seemed to be the sum total of what CAMHS could offer. There was no offer of an Autistic Spectrum Disorder assessment, although this had already been identified as a possibility by other professionals, because they didn't believe in labelling.

By the time Milly was 6 our family was in complete crisis and we were now experiencing increasing school refusal. Due to the apparent apathy of CAMHS, my daughter was finally referred for an ASD assessment by her Educational Psychologist. She was diagnosed with Asperger's following which there did not seem to be any post-diagnosis support, other than an ASD "Wise Up" course, and we felt like we were basically left to get on with it. And Asperger's just didn't seem a suitable fit or an accurate diagnostic profile for my child. Despite support at school and the implementation of ASD strategies, things continued to deteriorate and eventually we were experiencing full time school refusal. Life at home was nothing short of unbearable and by now my own mental health, emotional well-being and confidence was on the floor.

My lightbulb moment came when I was watching a TV documentary and a condition called PDA was mentioned. I googled PDA and I was literally blown away at how this cluster of symptoms fitted my child to a T. Local services were dismissive and so I funded a private referral to the Elizabeth Newson Centre. Milly was diagnosed with PDA and we thankfully did receive support and suitable strategies were implemented by social services and school. However, due to a lack of insight or experience in understanding and managing PDA, it was often left to me to educate those professionals around me who, thankfully, were willing to learn and help us.

Our local health services' response was to discharge Milly from all services, and in the years to come their treatment of both my child and myself was extremely poor indeed. Local health professionals refused to see her, citing that they did not have sufficient experience in PDA, and referrals to outside areas, for the purposes of prescribing and monitoring medication, were never implemented until some 18 months after my initial request for support. This followed a very fraught and emotional conversation with CAMHS where I accused them of gross neglect in their duty of care. Eventually this referral was secured and she was referred back to CAMHS but everything was by now too little, too late. It had taken years to reach the depths of despair that we now found ourselves in and it would take years to claw out of it.

I had been left to navigate the journey of PDA completely unsupported by local NHS services due to an apparent lack of interest, lack of recognition and vast lack of experience. Thankfully through my own research, tenacity and insight we made it through, but the journey that I have been on is not one that I would wish on my worst enemy. Milly and I travelled on a journey to hell and back, only the support from fellow parents kept me going and guided me through a very long, dark and lonely tunnel.

Below is a very short summary of how PDA presented in Milly and the impact it had on her and the family as a whole:

- Numerous, daily violent meltdowns that would last for hours. These meltdowns were caused by anything and everything and triggers were very difficult to identify
- Refusal and avoidance to do anything and everything either requested or suggested by others
- Complete inability to follow even her own self-imposed requests
- School refusal and virtually no formal education between the age of 6 and 12 years
- Social anxiety so acute that she became unable to leave the house at all for a period of around 2 years

- Complete control over the whole family which even included who could speak, what clothes I could wear, not being allowed to use the phone and the list goes on. Extreme role play which resulted in me not really knowing who my daughter was anymore because she spent all her time in one persona or another. Day to day living simply became her version of an alternative reality where she was the director and we were merely the cast under her direction
- Emotional breakdowns for both Milly and me. Milly experienced depression, crushingly low self-esteem and self-harmed. A family that became spit in two and barely able to function. A huge cost was paid by myself which involved my mental health being deeply affected and I too became socially isolated, unable to cope with or relate to the world outside of my home.

Due to the consistent use of PDA strategies during a period of several years, daily life is now, thankfully, transformed for all of us. Without this and the support of fellow parents I really do not think that we would have made it through. Our family life is unorthodox but it works for us and we are now a happy and strong family unit. Demand avoidance is still as high as ever, but we can now more successfully work around this by making the necessary adjustments and adaptations. Violent meltdowns are a thing of the past and Milly's social anxiety has greatly decreased (she is now accessing the community and managing to maintain equal and reciprocal relationships with peers). By keeping anxiety low and creating a social environment that meets her needs, Milly's need to exert control over others has lessened significantly. With increasing self-awareness and empathy towards others, she is also now developing her own self-management strategies. Milly is now a very caring and loving young lady who will go to great lengths to minimise the upset or disruption that her condition may cause to others.

With the correct support and understanding from her family, together with maturing years and self-awareness, Milly is now in the early stages of attending school once again. This is not proving to be a smooth ride, however. Attending school on a daily basis involves a lot of social exposure. I think we all underestimated the impact that this would have on her, despite the fact that she had been coping so well with her gradual exposure to the outside world.

Milly's environment, both at home and at school, is finely tuned to meet her needs but the main issue that she currently faces is being paralysed by the internal conflict of trying to comply with her own demands, her own wants and her own desires. The only way I can find to describe the situation is to think of a person with Tourette's or OCD - although they may not wish to compulsively tick or perform calming rituals, they are often compelled to do the opposite of what they want to do. Milly does not want to spend such large amounts of time at home, isolated and unable to attend school. But regardless of what she may wish to do, it is as if an inner compulsion not to do these things simply overpowers and overrides her wishes so that she is forced, against her will, to do the opposite. This stranglehold that her own mind has over her, it would appear, is the next stage in our journey.

Gradually, and with very careful strategies that have involved fine-tuning and adapting many of my old strategies, we are making very slow progress. A lot of this work is also down to Milly, as she struggles to navigate, self-manage and develop her own coping strategies to find a way to break free from the invisible prison that has incarcerated her mind for so long. The frustration, despair and low self-esteem that trying to comply with her own demands causes her is heart-breaking to watch and as a parent you feel

completely powerless to help. But we are determined that together we will make it through and that she will eventually be able to achieve her greatest wish, which is simply to be able to attend school without the all-consuming and raging internal battle that currently halts her progress.