



Zara

The moment Zara started school her previously calm demeanour vanished and her behaviour suddenly became very aggressive. We knew this wasn't naughtiness but had no idea how to move forward until PDA was mentioned. Implementing PDA strategies literally changed our lives, reducing 6-7 incidents a day to 6-7 a week! PDA is an exhausting emotional rollercoaster and completely takes over from traditional family life. It's essential for parents/carers to have their own coping strategies so that they can be strong, calm and organised enough to keep things on an even keel. PDA family support groups are incredibly valuable.

From the moment Zara started school we knew something was amiss as her previously calm demeanour vanished and her behaviour suddenly became very aggressive. She also started to avoid everything, was very repetitive in her actions and sensory processing difficulties became evident. Her existing speech irregularities didn't seem to explain these other behaviours so we met with our paediatrician who suggested autism. Even though that didn't seem to quite fit either, as Zara had good imagination and reasonable interactions at times, we agreed to try ASD strategies and review the situation in a year. Her behaviour continued to deteriorate at school and home, no techniques seemed to work, restraints became an everyday occurrence and many school exclusions followed. She just wanted to be in control of everything, and by the early stages of year one Zara was attending a Pupil Referral Unit two days per week.

We knew she wasn't naughty and that it was more a question of being totally misunderstood, but we didn't know how to move forward. It felt as though we'd completely lost our daughter and that she'd become someone else - a stranger - and we felt so very helpless and sad. But thanks to our insistence that Specialist Teaching Services become involved, we finally began our path to understanding as they suggested that Zara's behaviours could be a match for PDA.

Researching PDA and finding the invaluable PDA Society website was a massive 'lightbulb' moment! This feeling was cemented when we started trying out the recommended

strategies... it was nothing short of life-changing, we went from 6-7 incidents a day to 6-7 a week. We took our diary of these incidents, along with details of how we'd found PDA strategies to be successful where typical ASD techniques or traditional parenting had failed, to an emergency paediatric review. Having also observed Zara in school and spoken to the other professionals working with her, the paediatrician had no hesitation in diagnosing PDA, despite this not being a widely accepted diagnosis within our county. We secured an EHCP with recommendations for a specialist school placement as a result of the diagnosis, and as a family we felt immensely relieved to have an explanation for Zara's difficulties and the beginnings of a plan on how to move forward.

In addition to PDA, Zara has been diagnosed with a speech and language disorder and dyspraxia as well as having a variety of sensory difficulties. Due to this, we have learnt to allow her extra processing time, as her first answer is often the opposite of what she actually means. We've also found some calming strategies, such as chewing (special toys or gum), blowing bubbles and bouncing on a trampoline, to help her emotional and sensory regulation.

Zara's PDA impacts the whole family and literally takes over from traditional family life. It has changed relationships and friendships and requires immense understanding from everyone who socialises with us.

Zara is extremely possessive of and obsessed with her older sister, so we negotiate separation time and ensure that we also have plenty of individual quality time with our elder daughter. Tapping into the Young Carers system has been an additional life-line in this respect.

Zara's moods can change like the flick of a switch, so we're constantly on guard looking out for triggers or early warning signals so that we can make the necessary adjustments to avoid a meltdown. Exciting events or activities (like Christmas or birthdays) can be equally stressful and also require careful handling - at times it feels like she's trying to sabotage her own happiness, but really it's a fear of the unknown and her resistance is all to do with not feeling in control.

We realised after our diagnosis that finding support was going to be important, however none of our local autism support groups had a real understanding of PDA. I'd also been asked to attend a family resilience course to help with meltdowns at home, but I quickly grasped that they had no understanding of PDA either, so I stood up for the strategies that worked for us and educated the group! It was at this point that I realised that I was a good Mum and really understood my daughter. I also grasped that whilst I wasn't in control of Zara's meltdowns I could control finding us more help. So that's when I set up a local parent PDA support group. Being with other parents who are in the same situation has been really beneficial for me personally, and has helped us all realise we're not alone. It's provided an understanding and supportive community and continues to increase my own confidence as I help other families. I've also learnt to do what's best for my daughter no matter what anyone witnessing a situation might say - I've developed a thick skin in public even if the tears flow privately.

It's vital for us as parents/carers to take time out too, as living with PDA is a huge challenge and we need to be emotionally strong and highly organised in order to keep things on an even keel. PDA is an exhausting emotional rollercoaster where you have to trust your instincts and think quickly on your feet. If we're not feeling strong enough individually, our own emotions and reactions can add fuel to an already smouldering fire and cause it to flare or ignite!

There are many strategies we have found to be effective with Zara but these would be my top tips:

- Handling demands: We try to offer **carefully constructed choices wherever possible so she feels in control**, for example ‘Would you like to get dressed in your room or ours?’ or ‘If you put your seatbelt on we can leave now as you’ll be safe or we can wait here until you’re ready’. **Turning things into a challenge** or game (particularly a race) usually works well. Likewise making something sound harder or more complicated than an alternative choice often results in Zara choosing it. Or sparking her interest by starting to say something, then pausing and saying ‘oh no, it’s ok, don’t worry’. **Using a higher authority** than us often works too – for example ‘the Police say you must wear your seatbelt’ or ‘the Manager is closing the swimming pool’. Developing a **very indirect and un-confrontational style of communication** is key.
- Choosing battles & being flexible: Traditional parenting and conventional behaviour management techniques haven’t proved successful for us, so we **focus on rewarding the positive and making alternative suggestions rather than imposing sanctions**. Direct praise needs to be avoided and being willing to talk to her via a special toy or join in her role-play can help. Washing is a huge issue as Zara doesn’t like the feel of water, but showering with me and using my ‘expensive’ (so she thinks!) shower gel works a treat! Baby wipes and hand gels now have a lasting place in our home too!
- Thinking ahead: Zara craves structure but wants novelty and flexibility within it, **she likes to know what to expect so she can be prepared for changes and choices but doesn’t want any routine to be boring**. Any outing, even a quick nip to the shops, must be carefully orchestrated with enough time for discussion beforehand to agree calming, distraction and exit strategies as needed. Even staying at home requires forethought! We also have diversion toys (like therapeutic putty) to hand at all times. Any appointments are booked as early as possible in the day to avoid the accumulation of delays, and we ensure whoever is meeting her has been briefed about her PDA. Fortunately Zara likes food, but she prefers food with flavour so if we’re going out I often carry a pot of chilli flakes with me!
- Handling meltdowns: Sometimes panic attacks or meltdowns are unavoidable, and Zara has self-harmed, attacked others, destroyed property and regularly tried to jump out of windows or over banisters whilst being verbally abusive. The only real solution is to let things run their course, however restraint is needed when she becomes a danger to herself or others though this in itself can precipitate a full meltdown. If we are able to intervene in time, **distraction is the best method as this gives her the ‘get out’ that she desperately needs**. It can be hard to think up something suitable on the spot - especially as what works one day often doesn’t work the next – but our strategies include offering a favourite activity that involves blowing off steam or doing something a bit crazy like seeing who can be the first to throw a pair of knickers on someone else’s head! **Being consistently calm during meltdowns**, trying not to engage but occasionally offering a few reassuring words (“I’m here when you need me”, “love you” etc.) has proved the most effective strategy in bringing her anxiety down.

Every day is also a new day (sometimes every hour!), no grudges are held and the slate is always wiped clean. This can be hard, especially when we’re coping with the same triggers and incidents repeatedly, but for our sanity it’s essential! I always try to remember that **our daughter doesn’t choose to behave this way**. And whilst being Zara’s parent is undoubtedly challenging I’d also like to share some of her many positive qualities - she’s beautiful, funny, friendly, creative, helpful, incredibly thoughtful and extremely loving! She’s unique.