

As a baby

My daughter has always been anxious and clingy. She would not settle as a baby unless I was with her. Attempts to get her to sleep in her cot were futile and the sleep course I attended did not add anything new to the myriad of strategies I had read about and tried from countless books on getting babies to sleep. If I left her to cry in her cot, she would thrash against the sides and hurt herself. Cosleeping was the only way either of us got any sleep. I attempted many times throughout her years as a toddler to get her to sleep in her own bed, but she would not sleep and cried. Cosleeping has continued to this day and she is now eight. We attended a mothers' group for a year or so and this was fine while she was a baby, but once the others started to walk about, it became obvious that she was more fearful than they were and stayed close to me. I could not leave her with anyone. She became distressed if I was out of sight. At home, I had to wheel the highchair to the clothesline and to the bathroom, or she would get distressed by my absence and cry.

As a toddler

We attempted to go to playgroups, but again my daughter was clingy and demanding of my attention. She did not like me talking to the other mothers. Although we tried lots of different playgroups, she never settled. She spent a lot of time on swings or followed other children around, but did not really interact with them. She was wary of people who she did not know well and would not be held by anyone except her parents. If she was settled at playgroup for a few minutes and someone she did not know walked in, she would show real fear in her face and seek my lap. Even children playing about her made her anxious. She found their movements to be unpredictable and she would panic. She would not play in public playgrounds if they were busy, even if she had asked me to drive her to them. She has always been particular with food and tended to eat the same foods over and over again and then change to another food for a while. She would get upset if it was not presented in a certain way or was not a familiar brand. I always had to take a snack pack when going out as she would not eat food from cafes or even from relatives' houses. She has always been bossy and dominating, but at first I put this down to her being a strong willed toddler. She is an only child and has not had to share her things. If she did not get what she wanted, she would get very upset and take hours to recover. Her reactions were far more extreme than those of her friends and cousins. I learned to prevent her getting upset by avoiding social situations that triggered her and also by following her lead each day. I took a very child-centred approach to parenting her. She was bright and happy to explore and learn if it was on her terms. We got by for a few years while I hoped that she would grow out of her difficult phase. As she approached school age, she was not independent at all. She needed me to help her eat, dress, wash, toilet and sleep. I had never considered that she might be autistic, because she had always maintained good eye contact with me and reciprocated conversation. Other people had noted that she was difficult to understand, but I felt that was because she either went mute when out or talked too fast because she was anxious. She certainly had sensory aversions, but I did not connect them to autism.

Kindergarten and diagnosis

When my daughter started kindergarten, she desperately tried to fit in but struggled and her differences were more pronounced alongside the other children. She cried a lot and did not interact with the others. She watched a lot without participating and rejected the advances of children who tried to play with her. She was overly tired when I collected her and cried in the car. Once home, she would beg me not to send her back. Her recount of each session contained odd literal interpretations and sensory aversions. I discussed these with the head of education support at the school, who suggested she might have Asperger's. We saw a psychologist who confirmed this. I was surprised, because in my mind, she had never presented in the typical way that I had known people with autism to. I had taught a student with Asperger's and done some courses on teaching students with autism. However, when I went through all aspects of her presentation, autism did seem like the correct diagnosis and I respected the opinion of the psychologist, paediatrician and speech pathologist who assessed her. I then sought the recommended early intervention therapies.

Therapy

We went to occupational therapy sessions and my daughter did some desensitisation activities for her many sensory aversions such as touch. At first she cooperated and seemed to enjoy the sessions but once the novelty had worn off, she would not comply even though traditional autism strategies were being used like visual aids and star charts. I was able to continue the therapy at home where she was more relaxed. Over time, she resisted going to the sessions and completely refused many times, resulting in one session being held outside the practice door and two others in the car. One session began with a huge meltdown that lasted nearly an hour while three therapists tried to distract and calm her. I knew that she needed to retreat to the car and go home, but they insisted that she would calm down with their tried and trusted autism strategies. When this failed to work, the head of the practice conceded that I had an "extreme" situation. I decided that making her go to therapy was making her regress and so I backed off. She also resisted going to a daycare centre, special needs playgroup and small home education classes. I had no choice but to keep her home and home educate her as best as I could. It was not possible to socialise with friends or even have visitors over, as she would demand attention and get upset. It was very isolating. I attended a local autism support group but felt that I did not fit in. The issues being discussed were not relevant to my daughter. I also could not understand how all the other children were attending school without the resistance shown by my daughter.

Discovering PDA

Two years after my daughter had been diagnosed with Autism Spectrum Disorder, and after much difficulty managing her behaviour, I came across PDA. I happened to watch an episode of the UK documentary, "Born Naughty" and instantly recognised similar behaviour in one of the children diagnosed with PDA. I researched and at last felt that I had found an accurate description for her presentation. A friend of mine, who is an occupational therapist and has known my daughter since birth, also saw the documentary and commented to me that she felt PDA seemed to describe aspects of my

daughter's presentation. We have not looked back since discovering PDA . The suggested strategies have been effective and changed our lives for the better.

Living with PDA

Living with a child on the autism spectrum will always be challenging, but having an understanding of what motivates her behaviour is invaluable. We no longer try to apply traditional strategies for autism which were making her behaviour worse. There seemed to be an attitude during therapy of making a person with autism do something even if they were resisting. This does not work with PDA. Because everyday demands cause anxiety, it is important to disguise them or to make the person think that they are their ideas. This is not an easy skill to master. I have joined online support groups and these have been an invaluable source of support and strategies from other parents who understand PDA. The idea of allowing a child to be in control around adults is one that society has traditionally shunned. For an individual with PDA, it is a necessary strategy to accommodate his or her special needs. To force him or her to comply with demands that he or she resists due to anxiety is not only cruel but discriminatory. Society does not expect paraplegics to run against able-bodied athletes, so children with PDA should not be made to comply with the same methods of discipline that neurotypical children are managed by. My daughter is still educated at home. She will not take direct instruction, so instead learns through her interests. She has taught herself to read with just the basic phonics taught by me. She is very quick at understanding Mathematics, but will only pursue what interests her. She uses an iPad for much of her learning. If her interest is captured by any topic, she can pursue it to a mature level well beyond her age expectation. On the other hand, she needs help to wash, brush her teeth, dress, decide what to eat and for toileting. She has a buggy for travelling in when anxious in public places like shopping centres. She tries to control me throughout the day to soothe her anxiety and will not let me talk on the phone spontaneously. We do not have many visitors and if we do, we have to plan carefully how she will cope. We employ two support workers who come and work with her on socialisation and play skills. We do not travel or attend concerts, as her anxiety is too great and affects her body. Visits to the doctor and dentist are difficult.

Unfortunately, knowledge and acceptance of PDA is quite new among professionals in Australia. Once parents do find out about PDA and match the criteria to their children, they then have to seek supportive professionals and often educate them on the condition and how to help their children. Parents need as much understanding and support as possible. Their children are extremely challenging to manage and often mask at school or when with other adults, so that parents are not always believed about the anger and need for control displayed at home by their children. When upset, children with PDA can get angry, violent, abusive, need help but reject it, can harm themselves or others, and need hours to recover. PDA is a very complex and difficult condition to live with and manage. To the outside world, children with PDA can appear to be naughty rather than autistic. It is important that PDA is understood from the inside out rather than from the outside in. Individuals with PDA do not need judgement and discipline. They need understanding and support, and so do their families.