

Early Years

When our daughter Emily arrived fourteen years ago, she was the most beautiful infant I had ever laid eyes on. Caring for her was like looking after a beautiful big baby doll. She looked nice but there was very little reciprocated communication from her in the way of body language or verbal interactions. Throughout her first year of life, this was something that concerned me, along with difficulties of feeding and sleeping. I didn't let the lack of our interactions deter me from giving her all my love, devotion and time, and my time she took. Most days, the breakfast dishes sat unwashed in the sink until late afternoon. Her demands were so great for feeding and other routine tasks, that it was difficult to achieve much else. She began to walk at about the age of one and that was when my concerns became greater.

At age one, I would chase her around the house to persuade her to cooperate with basic tasks such as dressing, eating and bathing. What was wrong? Why was she resisting any ordinary task? Was she reacting to cow's milk? Did the 12 month vaccination give her autism? Did the gluten in her diet cause ADHD? Did she need to see a chiropractor to put her back in place? She fought me to not get into the car and resisted wearing a seat belt. I have vivid moments of when she fought me so hard in her resistance to wearing a seat belt that she beat me. It was from the age of one that our lives simply became a long and dark path of trying to find answers for her behaviour. This included dietary issues, seeing a chiropractor, nutritional supplements, ear, nose and throat, tonsillitis, asthma, overactive bladder, and with all those areas investigated and treated over the years, there was no improvement with her behaviour. My husband really wanted to try for a son but after Em I was adamant that I couldn't and wouldn't cope. Fate had other plans and when Em was almost five, her baby sister Katey arrived.

Over the years, the defiance to participate in everyday routines became more explosive and meltdowns became commonplace. They were more significant leading up to leaving the house for an outing. Every memory of an outing or significant event is tinged with some major incident of her screaming, yelling and being violent. Sometimes this could last for hours. This could set her off where she would try and hurt her sister or would have some unreasonable demand in her quest to have control and receive some instant gratification for some need she had suddenly required. I would be physically and emotionally depleted from trying to maintain a sense of calm. She began childcare and then school but the report back from her carers and teacher was that she was a passive child and that there was no evidence of the behaviours at home occurring at school. Things continued however, to get worse at home. With every part of the daily routine there was resistance : waking up, getting dressed, eating breakfast and so forth. It was exhausting. All my attempts to connect and interact were misinterpreted by her and she would rage at me. No matter what the outcome was, according to her it would be my fault. I tried different ways with her. She is the only child I have come across that does not respond to positive reinforcement or praise. That really stumped me. Strict discipline made it worse. I was at the end of my tether. Most nights I would sit in the back yard and sob to myself. Out there in the darkness and with the solitude of the open sky I would ask God and the universe why and to please help but no help was coming my way. I dreaded the weekends when we were all home because it would inevitably be filled with meltdowns, screaming and anger, and my attempts to resolve any situation being unsuccessful. As she progressed through the years at school, learning difficulties were also noted. Eventually a psychology assessment was approved. To support her with certain developmental skills, specialist therapy commenced. Her sight, hearing and auditory processing were all checked. They were fine, however tests revealed some learning

difficulties and a recommendation was made for occupational therapy which occurred over a period of some years but still made no improvement.

Getting Emily to school in the morning was chaotic. Getting her up and out of the house required two adults to cajole and prompt her. Once in the car, the explosive behaviour would continue and become worse.

ADHD diagnosis

Around the age of eight she had another referral to a psychiatrist who believed she presented with autism but she did not meet the criteria in her assessment and was given a diagnosis for ADHD with the recommendation of psychotherapy and medication.

A lot of the incidents that occurred with Emily would mystify me. I could not understand what was behind them. She had no concept of authority or of the pecking order between an adult and a child. She could mask her difficulties and appear like a completely different person, usually when someone unfamiliar was around. When we saw glimpses of this different, nicer person, we were perplexed at how the two opposite personalities could come from the one person.

Another incident that baffled me was when we were on holidays down south. We took our torches at night to see if we could spot possums. Em did not want to cooperate with the idea of flashing our torches into the tall trees to spot the white tips of their tails. She ran off into the darkness. My husband and I were concerned for her safety, ran after her and both tried to hold her in place as she tried to escape from our clutches. Another couple were coming towards us and as they passed, she called out to them, "Help! I don't know these people!" referring to us. Fortunately, the couple did not think it was reason for concern and continued on but this incident frightened and puzzled me. It showed that morally she would not stop at anything to defy our requests.

By now Em was being treated for ADHD and taking medication but still something was not right. She was not really responding to the medication as well as I thought she should. She continued to show a lack of understanding of others' emotions.

Autism Diagnosis

I started reading about autism in girls and how it presents differently than in boys. I called our state autism association. I asked them if they had any paediatricians who they would recommend. They gave me the name of one who we saw eventually, I was surprised at her brusque manner and how she appeared quite irritated with Em's presence and behaviour. She flatly said that my daughter did not have autism because she gave eye contact. By that time, I had been to a seminar with Professor Tony Attwood and even managed to have a brief chat with him. I became more assertive with this paediatrician regarding Em being assessed again for autism. It was crucial for Em and us to get the right help. Eventually, she agreed to write a referral and Em was diagnosed with Autism Spectrum Disorder Level 1, which took another eighteen months. This occurred only because we jumped on a plane and flew to Melbourne to meet with a psychologist there who Professor Tony Attwood had recommended to me. Once back in Perth, we had to find another paediatrician. We finally did find one who was supportive and non-judgemental but it had taken ten years and four attempts.

Now newly diagnosed with autism, it would be another two years until we were able to receive services from one of the government funded disability organisations. When the team first made contact, I said to them with a great sense of hope, "I have been waiting twelve years for you." We had self funded services for most of her life but sadly the new services did not bring about change. Even with a team of specialists supporting our family, her behaviour spiralled out of control. On one of the specialist's home visits, she was asked to draw a picture of how she felt about her mum. She drew a picture of herself with a bloody knife held in her hand.

She will stop at nothing to get her own way and has honed the skill of being argumentative and hurtful to achieve control over a situation. This can be very difficult when she has no sense of when she has pushed someone's buttons and pushed them to the edge. Most people and children can see when an adult has been pushed to their limit but she does not. She will continue with her abusive language and at times this has put us in a situation where we have lashed out at her in sheer frustration and also for her to realize that she needs to stop. On one occasion, she called the police who came to our house and spoke to her. Then they spoke with us and left with no further word. The department of child protection have been involved with her on several occasions, when she has called them and when the school has called them and police due to a couple of internet photo scandals.

Destruction

Every interaction with her is met with defiance, an argument or resistance. If we try to put some boundaries in place such as having the internet off at 10pm, she will argue with all of her might to persuade us to give in. If she is not successful in this manner, then the destructive behaviour will begin. We have had specialists work in our home and offer advice from observations. Once, encouraged by my sister, who has written behaviour management plans for teenagers with autism, I tried to shape positive behaviour (in one instance to pick up her wet towels off floor) by turning off the internet in increments of time, increasing with each warning and refusal from her. This caused her so much distress that she was willing to scream and cry for the whole weekend rather than pick up those towels and by Monday morning we were both depleted of any energy and the towels were still on the ground. I continued this behaviour plan until three weeks later when I sadly realised this too was not going to work.

Currently, life in our home is totally dysfunctional. Her behaviour at times is not only abusive and violent but also destructive. She has taken the scissors to my clothes, phone charger cord, my diary, curtains and tablecloths. She has stolen pieces of my expensive jewellery, credit card and make-up. She has vandalised the inside of my car, her bedroom, smashed plates, glass picture frames and damaged electronic devices in her rage. She has taken a lot of pleasure in locking me out of the house if I step outside. Recently, she found a lighter and threatened to set the house on fire if she did not get her own way. Living with this type of behaviour is like living in an abusive relationship. The amount of control she exerts over me is a deprivation of my liberty.

For some reason Em feeds off an energy around Katey. She acts giddy in her presence and has to touch, annoy and hurt her. Em will always dominate any attempt at play. She will tell her sister that she hates her so much and that she wants to kill her regularly. Strangely, Em will tell her sister how to behave but then will go ahead and do exactly what she told her sister not to do. We spend a lot of time trying to keep them apart so that Em is calmer. Katey, now ten, has grieved the loss of a protective big sister.

It has saddened me that not only has she bullied other kids but that she has spread rumours about children to others if she has perceived that they have done the wrong thing to her. I have parents approach me about what my daughter has done to them. It seems that if she cannot control them, she will control how others think of them. She is addicted to her social media and is unable to be away from Wi-Fi. Some of her inappropriate behaviour amongst her peers is evident in these internet platforms such as Snapchat and Instagram.

She can be very provocative and say things like, "I am gonna be a stripper when I grow up" or "Will you let me smoke weed?" I seem to have very little influence which is such a difficult thing for a mother to endure. She will find the most hateful language possible like, "I will slit your throat if you go into my room" or "Why don't you go hang yourself?" If I burst into tears she simply does not get it. She will say, "Stop fake crying". She doesn't just say, "Oh I hate you mum!" like most teenagers. Her speech is coming from a place of real imbalance and she shows no remorse or emotion towards her mother who is visually upset. I fear as what the future holds for her and for us.

I have tried to connect with her all her life. It is like she has this thin veil over her where I can see her but I cannot get to her. My influence and my logic is misinterpreted by her. With suggestions from family therapy, I have tried things like tapping into her interests etc. With the arrival of puberty she has rejected my advances more so and she continues to treat me on a scale between disdain and hostility. For a mother, this is the most heartbreak thing to live with. I am a sensitive soul and even though people say not to take it personally, everyday it reminds me that there is disharmony and someone who is very angry and choosing to put that anger onto me.

Over the years, she has seen many psychologists but they just get to a point where they seem to give up on her.

Discovering PDA

The last few years have just been one incident after another at school. Presently with high school, every second day there is an email from a teacher about some issue that she is having at school. I spend all my spare time 'putting out fires', advocating for her, and attending appointment/s with our local coordinator for disability services, psychologist or school counsellor. She does not show awareness of authority and the way she has treated teachers has caused issues at school.

The onus is on me to do something about her behaviour. The school does not have the expertise on how to handle her behaviour so they get in contact with me. The psychologist does not know what to do so she throws it back on me. It is just an exhausting, difficult and complex circle.

I really felt at an all time low recently when it was reported to me from school that she had started self-harming. I told our family psychologist that with all the support over the years, this is what it has come to . . . a child who is self-harming and a parent who no longer has the emotional strength to care for own her child. This is coupled with her being able to mask behaviours when she stays with my sister or mother and yet be so hateful towards me. I really thought, "I no longer have anything left in me to give her and if what I am giving her is causing all this, then she should live with someone else."

After a heartfelt discussion with the school counsellor, due to the self-harming incident, I started saying to him that there is something more going on with my daughter than autism. I

know lots of parents that have children with autism and they find them absolutely delightful and God's gift to them. Why is my life a living hell? Is there something else? I was also distressed because her lack of emotion, remorse and her ability to connect with me, her primary caregiver, was showing a tendency towards sociopathy. It was then that the counsellor offhandedly mentioned Pathological Demand Avoidance. He said that one of the teachers said if Em was in the UK she would be diagnosed with PDA. From this conversation I searched with scepticism and read about PDA. From what I read, I was suddenly enlightened and her behaviours started to make sense. Her behaviour aligned with the PDA profile. Her great need to avoid anything that was imposed on her by another, was due to her heightened sense of anxiety. Since finding out about PDA, I have read so much on the topic. One particular book written by Jane Sherwin who chronicles her life with her daughter, resonates with and validates my own experience. I also started to feel very angry that this has been around for a few years, and out of all the professionals I had dealt with, there was no mention of it.

Over the years, I had experimented with many ways to interact with her to eliminate the aggressive responses with little change. After reading about PDA, I have realized that because most of my interactions with her are a routine request, this could be why she has the anger directed at me. I have rephrased the way that I speak to her with no direct instructions, and I carefully word it so she does not feel like I am exerting power over her. Now I will say, "When do you think you might like to get out of bed?" This seems like a really strange way for a parent to talk to a child but this type of communication has been the one thing that has kept her calm in the morning.

My lack of knowledge of the right strategies for interacting with her up to this point has caused a lot of grief for all involved. After discovering PDA, I shared information with the specialists who work with us, and none of them had heard of it, even though they specialise in autism. My psychologist asked me why it is important for me to identify Em with the PDA profile. I was surprised at her question because I thought the answer would be obvious. My reply went something like this, "It is important because the strategies traditionally used for a child with autism do not work and there needs to be an acknowledgement that there is a different approach. It is also important to recognise that there are other children like her and as a parent connect with these other parents in order to share stories and support each other in dealing with such complex and difficult behaviour."

My daughter tells me on a regular basis that I am a terrible mother who has failed her and yes, I have, because that is her perception. Knowing the strategies used for dealing with children who have PDA may help me change that perception. For two, once confident, educated parents, we have been unable to manage this mental torture of living with a child who does not understand or recognise her own emotions and those of others whilst being defiant and oppositional with every interaction. Despite all of this, we have never wavered in our unconditional love and advocacy for her. Knowing about PDA and having the support of other families who are going through the same issues has been a life changer for me. I no longer feel alone. Using the suggested strategies on how to approach her and word things in a way where she feels she has control has been a huge step forward.

This is why it is important to raise PDA awareness in the community. I would not want any family to go through the suffering, judgement and feeling of isolation that we as a family have experienced.