

PDA THOUGHTS!

How PDA presents and affects our daughter, the impact on family and the strategies that we find successful

Introduction - What Is PDA?

PDA stands for Pathological Demand Avoidance and highlighted below are the key points as described by **Phil Christie, 2015, The National Autistic Society**:

Pathological Demand Avoidance (PDA) is now considered to be part of the autism spectrum. Individuals with PDA share difficulties with others on the autism spectrum in social aspects of interaction, communication and imagination. However, the central difficulty for people with PDA is the way they are driven to avoid demands and expectations. This is because they have an anxiety based need to be in control.

People with PDA seem to have a better social understanding and communication skills than others on the spectrum and are able to use this to their advantage.

The main features of PDA are:

resists and avoids the ordinary demands of life

appearing sociable, but lacking depth in understanding

excessive mood swings and impulsivity

comfortable in role play and pretend, sometimes to an extreme extent

language delay, often with good degree of catch-up

obsessive behaviour, often focussed on people.

As the term spectrum suggests, individuals are affected in different ways and to varying degrees.

Often in cases of PDA there will have been a passive early history, but this is not always the case. It is believed that there may be neurological involvement in some cases, with a higher than usual incidence of clumsiness and other soft neurological signs.

Just as in autism and Asperger syndrome, people with PDA can have difficulty processing everyday sensory information such as sound, sight, smell, taste, and touch. They can also have vestibular (balance) and proprioception (body awareness) difficulties.

For more information about the diagnostic criteria and professional understanding of PDA please visit <http://www.autism.org.uk/PDA>.

Personally, we have found that children with PDA can be exceptionally loving and thoughtful however, most of the time, they do not like being asked to do things i.e. they don't like direct requests or demands. They feel anxious and need to avoid doing the things asked of them because they don't feel in control of the situation. It is often not the activity itself which is hard but the expectation that they need to do it. This can include seemingly simple things like getting out of bed, brushing of teeth, eating food and going to the shops! Therefore, alternative, and often very creative, ways of getting our children to achieve the things we require them to do, need to be found.

The Journey To Diagnosis

In September 2013, our daughter began to attend school in Reception Class and we knew something was amiss because her behaviour suddenly became very aggressive and violent; she also became very repetitive in her actions, wanted to avoid doing anything and sensory processing difficulties started to become evident.

The speech irregularities, that we knew she had, didn't seem to explain these additional behaviours so we discussed this with our Paediatrician who suggested Autism, but that didn't seem to quite fit either as she had good imagination and reasonable interactions at times. However, we agreed to try ASD strategies and review the situation in a year.

Our concern and frustrations grew as her behaviour and aggression continued to get worse. No technique seemed to work and by the summer term restraints were nearly an everyday occurrence and many school exclusions followed. We now regularly saw avoidance with uncontrollable violence at home as well as within school. It was a relief to arrive at the school holidays but the daily challenges didn't stop!

On returning to Year 1, the situation deteriorated further and by October 2014 she was attending the PRU (Pupil Referral Unit) two days per week. We knew she wasn't naughty, just misunderstood but we weren't sure how to move forward. It felt like we had completely lost our daughter and she had become someone else, a stranger; we felt helpless, frustrated, angry and sad. In February 2015, we insisted that the Specialist Teaching Services become involved and, following a chat with the PRU they thought her behaviours could be a match for PDA (Pathological Demand Avoidance Syndrome) an autism spectrum disorder.

Not having heard of this before, we researched this ourselves and fortunately found the PDA Society's web-site that has lots of fantastic information and strategies to help. We had a massive 'light bulb' moment! Our views were cemented when we started trying the strategies; it was totally amazing and life changing, we went from 6/7 incidents a day to 6/7 a week. Major panic attacks / meltdowns also reduced from 2-3 a day to 2-3 a week. Interestingly, to us, she also scored highly, 72/78, on the Extreme Demand Avoidance Questionnaire. This is a tool that can help identify individuals who may have a profile consistent with PDA (identifying scores: 50+ for age 5-11, 45+ for age 12-17).

We attended an Emergency Paediatric Review in March 2015 and took with us written diaries on how we'd seen PDA strategies be successful compared to ASD and typical parenting ones. Our Paediatrician had previously seen us in clinic and had then visited mainstream school twice to both watch and talk to our daughter, as well as the teaching staff; She'd also spoken to the PRU and other professionals who were working with her at the time.

Unbelievably at the time, it was not necessary for us to present our material because, from what she had witnessed personally and from what had been reported, she had no hesitation in diagnosing PDA, despite this not being a widely accepted diagnosis within our County. An EHCP and a specialist school were recommended; the relief was immense!

Our EHCP was completed by May 2015 (paperwork had been submitted in the January but we needed the diagnosis to successfully conclude the process) and she started her specialist school placement in September 2015, just before her 7th Birthday.

How PDA & 'Autism Like Traits' Present In Our Daughter

We have noticed that when our daughter's anxiety is lower, that the more typical traits of Autism become far more evident and clearer to see. When her anxieties are high the many 'more typical autism traits' can often be camouflaged by the demand avoidance and subsequent challenging behaviour.

Demand avoidance & control is a key feature of our daughter (age 8). She has a constant anxious state that necessitates the need to always feel in control of her immediate environment including the people in it. This is often achieved by an anxiety driven need to avoid all demands and expectations presented to her, whether explicit or implicit and to control the actions and interactions of others. Unlike many children with a more typical presentation of ASD she appears to have sufficient social awareness and imagination to manipulate people and situations to avoid demands.

Avoidance will also occur with activities she's been looking forward to or desperately wants to try and it can at times feel like she's trying to sabotage her own happiness; but really, it is the fear of the unknown and therefore her resistance to not having the control. If her emotions escalate and she feels she can't control any given situation she gets verbally and physically abusive leading to a bigger panic attack. If distraction doesn't work at this point we enter meltdown.

Our daughter's strategies to achieve control, similarly to those of other children with PDA, consist of negotiation, distraction, delaying tactics, excuses and playing helpless & incapable; so that she believes things are very much on her terms. Very often, when these strategies fail or during times when she just cannot cope with daily life and the many demands that this entails, she may experience anxiety driven panic attacks, which can be aggressive and violent in nature.

When trying to avoid a request/activity our daughter is great at trying to change the subject, arguing, negotiating a change, suggesting alternatives, giving reasons why it can't be done or suddenly feeling too ill to do something. The avoidance can take much longer than the task required! Conversely she can be friendly, creative and incredibly thoughtful and loving. She's a bit of a mystery!

Delayed speech was present until age 5 but although there was a significant catch up our daughter continues to fall significantly behind her peers academically. She has now been diagnosed with a speech and language disorder in addition to having dyspraxia (a disorder affecting fine and gross motor co-ordination skills) and a variety of other sensory difficulties.

Social Skills are also under developed so board games or structured activities can be very difficult. It's challenging for her to take turns and share and, most of the time, she'll hate losing so will try to cheat to ensure she wins.

Maintaining friendships and playing with peers (and cousins) becomes more challenging the older she gets as their play has developed and moved on but she continues to like activities which are considered 3/4 years below her age group, unless it's technology based i.e. Minecraft then she can almost surpass her sister!

There is also the inevitability that most of her current friends will drift away as they are unable to cope with the demands and control placed upon them when trying to play; and that does fill me with sadness. However, she does currently have a couple of very special friends who seem to understand and accept her unconditionally which is wonderful and, also offers us hope. We do recognise though that much of this acceptance is due to the willingness of the parents to learn and teach their own children about PDA and how this will affect their friendship, and for this we are very grateful.

Self-regulation is challenging for our daughter but she is beginning to learn a few techniques to help herself, in relation to her behaviour, and calming herself when upset i.e. chewing something appropriate, rocking forwards and back or from side-to-side (often on her 'teeterpopper') and jumping on a trampoline. She can be very repetitive in her actions too i.e. stimming, although these can sometimes cause additional challenges e.g. the flicking on/off, of light switches and safety issues; needing to have her bottom constantly checked to ensure it's clean and then constantly wanting clean underwear; spinning round and round refusing to stop but making herself feel sick.

Empathy can be seen on occasion but the integral understanding of emotions and how they affect her and those around her is lacking. Crying in happiness is a completely alien concept and when seen in others will immediately raise her anxiety; I must remember not to cry on my birthday next year when I'm given a very thoughtful handmade gift!

Obsessions with people rather than objects/toys are very common in children with PDA. Our daughter is possessive and obsessed with her big sister, aged 11, to the extent she follows her everywhere and just wants to be with her all the time. We now negotiate and agree separation time; often, we need to say that, it's her sister's homework time, and that it's the head teacher who says she has to do some! This can change when her sister brings a friend home, as the friend often becomes the obsession.

We also need to remember that our older daughter needs reassurance and special time alone with us as her sister's behaviour affects her emotionally; it's easy to put it off as she's very mature and understanding for her age but it's important we have quality time together too. Tapping into the Young Carers system has been an additional life-line but more surprisingly has been fully accepted by our youngest!

Other obsessions and repetitive routines can include shopping and buying toys/games but then she doesn't, really, play with them after they have been purchased. Our daughter loves watching the same films/programmes repeatedly and we often see stimming for self-regulation as mentioned previously. When her anxiety is lower she will take her toys out, line them up & then put them away again in, exactly, the same spot every time but she is generally always meticulous about the location where things are kept; everything has a specific place and her memory is quite amazing.

Rapid mood swings often occur within children who have PDA. When feeling less anxious and in control many of these children can be friendly, charming and very engaging. However, this can be extremely confusing and can lead to the feeling of a "Jekyll & Hyde" character particularly when moods suddenly change like a flick of a switch, from calm to meltdown!

We see daily changes of persona and regular outbursts within our own daughter and therefore we find ourselves constantly watching for triggers, or signs, and then adjusting approaches to try to avoid these moments. No sleeping on the job is allowed!

It should be noted that dealing with excitement can be just as stressful and challenging as dealing with anxiety and, requires very similar strategies. Easter, Christmas, Mother's Day, Father's Day, Halloween, Guy Fawkes, plus all birthdays and holidays are major trigger points in our annual diary.

Masking (hiding emotions) is something that many children with PDA learn to do. They often find it very hard to moderate and regulate their emotions and so they learn to 'mask' their true feelings until they feel safe. Our daughter is now a natural at this technique, she will only show her anxiety in an environment and with people she trusts.

This wasn't always the case, as she initially showed emotion and had panic attacks within her mainstream school. As triggers continued to be missed these panic attacks often led to meltdowns and violence. Due to the way these incidents were then handled, it resulted in a complete breakdown of her trust and a refusal to engage. It was at this point she learnt to 'mask', until she was with someone she fully trusted or at home in a safe place.

She also masked for nearly the first year at her new 'specialist' school, but she's slowly starting to trust a few key people and, with their willingness to adopt PDA strategies, her ability to engage with them and therefore ultimately learn is improving.

Eye Contact can be more easily seen in PDA children but equally can be avoided. For a long while our daughter would only look at us through a mirror. She will rarely look at anyone when asking or answering questions and often her head is tipped towards her chest so hearing what she's saying is more difficult too.

Role-Play and pretend or imaginative play can become obsessive and sometimes a child genuinely believes it's real. 'Rosie Dog' is a regular visitor to our house when our daughter feels she can't cope, but you can sometimes ask Rosie Dog to do things, which result in compliance rather than refusal! Equally dogs don't work they play so if you ask at the wrong time for help with say setting the table or getting dressed, the reply might be "dogs can't do that". She has also become Rudolph at Christmas and more recently has chosen to be Skye or Everest from Paw Patrol.

Occasionally she'll act out a scene she has watched on TV or experienced in real-life; more frequently she'll assume a different character but carry on with the activities she's trying to achieve. On the odd occasion, we also, need to assume characters she's allocated to us until she says it's ok to stop.

Our daughter's role-play, which can include a very straight and serious face, has also confused many people into believing that some of her excuses and elaborate stories, with incredibly vivid detail are true. Rather than something that has just been made up to avoid a demand!

Sensory sensitivities seem to vary depending on how she is feeling. She doesn't like loud, unexpected or high-pitched noises and if there is an accumulation of noise she sometimes chooses to wear snugs, ear defenders; clothing can be too scratchy, stiff or tight; food can be too bland and different textures can't be mixed together. Busy spaces cause overloads and although having and playing with friends are important to her these seemingly normal activities usually end in meltdown.

Strategies We Find Successful With Our Daughter

We try to offer choices wherever possible so she feels in control: Would you like water or apple juice? Shall we go to the park or play in the garden? Would you like to get dressed in your room or ours? Shall we wait here a few minutes or carry on? If you put your seatbelt on we can leave now as you'll be safe or we can wait here until you're ready. If you have kind hands we can... [find a sweet/biscuit, play a game, etc.] ... otherwise we'll need to wait. Oh, silly Mummy I'd forgotten we were going to.... shall we do it now or in a minute?

Distraction is a fantastic technique but can be the hardest to achieve especially when you need to think quickly. Normally for us it also needs to be completely different to the activity that is causing distress i.e. blow bubbles, push/pull game, drawing, play in tent, go for a walk, have a tickle, play with balloons, chewing/eating something, etc. The quickest way is to offer an iPad or phone to play on but then trying to stop that activity can bring its own challenges!

Unfortunately, what works one day won't necessarily work the next so it can be a guessing game. We have been known to pull all her knickers and socks out of her drawers and see who can be the first to get a pair of knickers on someone else's head!

Turning things into a challenge or game and particularly a race usually works well: race you to your toothbrush; bet you can't put your shoes on before me; who can see where we parked the car first; who can pick up the most toys you or me; shall we set the table for our restaurant;

I think I've forgotten something can you remember what we said we'd do... [before we get changed, go to bed]?; would you be able to help me with...; our challenge is to work out the answer to these sums, etc.

Playing a racing game does mean that we, must, lose and be prepared to be tricked into going the wrong way so she gets a head start! If she tricked us we must also let her gloat and say how she won. Sometimes starting to say something, pausing and then saying "oh no, it's ok don't worry" will spark an interest i.e. "I was wondering if [pause], oh no it's ok, I'll do it...", "What?" says a voice. "I was just wondering if you'd like to find the right number of knives and forks and see if you can lay the table, but it's a bit of a big challenge, I'll do it" ... usual type of reply "no that's easy, you're silly, I can" then rushes off at 90 miles an hour to do it!

I'm not sure racing will continue to work as well as she gets older but I think well-constructed choices, challenges and allowing a little negotiation will successfully take over.

Setting challenges and making something that you want her to do sound more complicated or too hard than another choice will often result in her picking it, but you should be prepared to accept the easier choice if chosen!

Using a higher authority than us often works too i.e. it is the Police who say you must wear your seatbelt to keep you safe, the Doctor says sun cream is important to protect your skin, the Manager is closing the swimming pool.

Allowing extra processing time for all statements made and repeating certain requests to ensure the answer she means is obtained is essential due to her speech and dyspraxia difficulties. The first answer she says is often the opposite of what she means and, no is often used for yes and vice versa. The language she articulates can be basic and muddled i.e. him/her instead of he/she, with confused structure, but that said her understanding and use of more complicated vocabulary together with her knowledge of certain concepts is viewed as above average. Therefore, there is potential for academic success, if we can find ways to help her get to grips with the basics, and feel comfortable learning. Hopefully this will then encourage her to pick up a book and pen, or alternatively sit at a computer!

Maintaining discipline is important, as there are boundaries in life that need to be learnt and understood. It can be challenging identifying PDA behaviours from inappropriate or plain old naughty ones but consistency and learning your child's triggers plays an important part in this. Within our family we might adjust what we consider to be acceptable, compared to her sister with a typical understanding, but there are still rules and appropriate acceptable behaviour is very much expected.

Traditional behaviour management techniques have not proved successful to us. Timeout, reward/sticker charts, etc., are basically meaningless because the understanding behind them is not present within our daughter. Threatening to take things away doesn't work either as she just says she doesn't care. It is **better for us to reward the positives** and to offer a spontaneous reward i.e. a glo stick at bedtime, extra time playing on her iPad, time to watch a favourite TV programme and extra time playing with mummy etc.

From time-to-time she does like collecting marbles as a full jar equals pocket money but it's not a driving force and she can go weeks without wanting to put them in. It is also pointless saying things like no, stop, don't; they're demands so they just make her carry on. **Alternative words or suggestions need to be made** e.g. I'd like you to consider doing.... instead; climbing here isn't safe let's go to the park/blow some bubbles/find your den; I'm stuck could you help me with...; you're clever, I need your expertise to... etc.

Reducing the demand to a smaller and more manageable demand also works well, for example simple 'get outs' can be useful in public places i.e. When thank you should be said to a stranger but that might be too hard we might suggest, "how about a nod or smile". Saying goodbye is difficult too so we remind her "waving is fine".

Safety nets are essential, so we always have an exit strategy and/or something that she can do or say for when she feels she needs help. Often she'll hide in my long cardigan that I now wear solely for this purpose!

Praise can be very tricky, but it's a natural thing for a parent to want to do. We find direct praise is not tolerated unless our daughter instigated the whole activity; instead we try to praise her via her favourite toys or talking about her in an overly loud voice to a family member or friend. We often put special pictures on the fridge for others to see but we don't specifically mention it. If she doesn't like the praise, particularly if it's a picture or piece of work she's created, we should be prepared for its destruction!

Routines and planning are other important factors to help reduce anxieties. Our daughter craves structure but there must be novelty and flexibility within it. She has a rolling weekly timetable which provides the demands in a non-threatening way i.e. highlights school, dentist, visits, if someone is out, birthdays, etc. but has no specifics to allow flexibility. She basically likes to know what to expect so she can be prepared for changes and choices but doesn't want any routine to be boring. We initially used simple language to talk to her about activities although as she is getting older more complicated sentences seem to capture her interest & attention more!

However, changes to her routine often spike her anxiety too i.e. a different taxi turning up to take her to school even if it has the same driver and chaperone; any transition from one activity to another despite this being planned and often wanted; something she has decided she wants to do but as she's only thought and planned it inside her head, and not verbally articulated it to us, we don't do. The changing of the clocks particularly from summer to winter time when the nights draw in causes much distress for our daughter too as she doesn't like the dark unless she has chosen to make it so i.e. by going into a blackout tent or covering herself with a blanket. Every October for the last four years we have seen a significant spike in her anxieties. Life can be very complicated!

I have seen, however, that several children with PDA do prefer no prior knowledge of planned activities, and therefore the appearance of spontaneity works best. It's important to remember that every child is unique!

We allow extra time to get anywhere and have diversion toys to hand if she's struggling (therapeutic putty, silly popping toys and sensory tunnels are great). Remaining calm in everything is the key, which is incredibly hard especially if she's trying to take her seatbelt off on the motorway! We try not to have too many people coming & going from our house and have had to re-evaluate the places we go to so our daughter feels safe & not overwhelmed, advanced planning is essential; even to see family. Activities that most people consider normal we would often have to avoid like: going to the cinema, swimming, activity parks, play dates and sleepovers with friends/grandparents. We usually need to stay with her to give her confidence and to help interactions with others although in certain circumstances she can manage this herself.

Before our daughter started school, she attended dance classes and even danced on stage at our local theatre with a full audience. It appears that anxiety has now taken over her life, particularly as she gets older and her understanding grows, it is very debilitating in so many unseen ways.

All appointments whether for the hospital, doctor, dentist, opticians, etc. must be planned well as these are unknown and anxiety provoking events. We try to arrange appointments as early as possible in the day to avoid the accumulation of delays and ensure whoever is meeting her has been briefed about her PDA.

Visiting the hairdressers is another trigger and sitting still is a big challenge. Fortunately, we have a wonderful understanding stylist with lots of patience who just seems to have the knack with her. The salon is the only place she will have her hair washed without complaint, slightly dried with a hairdryer and brushed without shouting!

Discussions are important to try to find out how our daughter is feeling about something, however we find they often work better if we have planned these first rather than ask outright. We need to make suggestions to her, allow for negative answers, offer a couple of ideas and see if she will then counter offer and suggest her own thoughts. After several minutes of almost negotiation we do often get to the bottom of the issue but it is hard work. It's not always quick either as it can take a few attempts over a couple of days or even weeks.

It's the same for trying to overcome issues; suggesting ideas, allowing counter suggestions and giving the ability and time to process, and ultimately own the idea herself, offers by far the best solution.

Our daughter didn't want to go to bed but we couldn't work out why as she was always really tired and once in bed fell asleep quickly. We planned a discussion listing things we thought could be the cause: lighting, bedding, PJs, shadows, etc, but unexpectedly it was Daddy coming home that was upsetting her, she got too excited and so wasn't able to go to bed! The only thing that resolved this was for Daddy to stay away until she was in bed and asleep. Had we not had a structured plan and allowed time for her ideas I don't think we would have reached this conclusion so quickly; it was still hard to implement as it felt so unfair on my husband but after reassurance from a few key people we went with it. Six months on we were able to have another discussion and he is now allowed home when she is in bed and even allowed to read a story! She just needed the reassurance of a fixed routine and a way to tell us!

Sensory issues vary depending upon our daughter's anxiety. The chewing of clothes is a constant feature but more recently a 'chewbuddy' is reducing my re-sewing of jumper cuffs! When out and about chewing-gum is easy to carry around and very useful to help calm rising emotions, as is asking her to carry a weighted rucksack or bag.

Sensory tunnels/tents and weighted toys help her to calm when in doors and offer an easy way for her to self-regulate her emotions. From time-to-time she also chooses a special cuddly toy that we can talk to and then ask it to look after her. Sometimes the toy can even ask her to do things!

Brushing of hair is another issue so she now wears this in plaits most of the time, as it doesn't knot as easily. When brushing applying firm pressure to the top of the head or holding the hair so it doesn't pull is key too.

Food can cause many challenges for children with ASD but we are fortunate that on the whole our daughter likes food. It just needs to be separated on a plate, sauces put on the side and the food itself must have flavour. I have been known to carry a pot of chilli-flakes with me!

Meals choices cannot be repeated too quickly either as she likes variety (unlike some more typical children with autism who like the same food every day!) and occasionally, she will go off a certain colour (often green) or type of food and this must not then be put on her plate if we want her to eat! We do have several food intolerances to deal with and constipation has been an issue since age 2 but Movicol keeps this under control if we can ensure the medicine is drunk in the morning; a variety of drinks and a choice of bottles or cups to drink from work well, but no milk as it curdles in the tummy!

Eating out is also a frequent request despite the fact she finds it hard coping with people, food touching on the plate, slow service, etc. and therefore, this activity, normally ends in some form of panic attack.

Personal Hygiene is a generally a huge issue as our daughter does not like the feel of water! Just getting her to wash her hands after going to the toilet is a challenge but bathing/showering is now a once a week task as it can take several hours to persuade her to have one. We're trying to instil the importance of cleanliness now as this can't be stressed enough through puberty and when she'll have no choice but to increase and change her habits!

We have found that Epsom salts make the water feel softer to her in a bath, but showering with Mum is currently the most effective solution so she can use my 'expensive' shower gel, or so she thinks!

We encourage the brushing of teeth twice a day but if we manage one reasonable attempt we're happy. We've come to realise that baby wipes and hand gel have found a lasting place in our home!

Panic attacks/meltdowns occur if we've missed anxiety triggers or for some reason our daughter's switch has just flicked. During a panic attack she will begin to get aggressive and can shout, hit, pinch, swear, try to wee on us or do something else for shock value. However, she generally knows what she is doing and retains a relative element of control that means she can often be distracted.

If we've not been creative enough with our distraction or when she just can't keep control any more, she's in meltdown, and then doesn't know what she's doing. Hitting, punching, kicking, verbal abuse etc. get much worse; she tries to self-harm or puts herself or others in danger. She's been known to try to get knives, run away, jump out of windows and over banisters. The only way to fully stop meltdown is to let it run its course, however restraint is needed when she is a danger to herself or others. She usually collapses emotionally drained and exhausted at the end and is tearful and very clingy. It can often take 1½ times the length of the meltdown itself (or restraint) before she is fully calm again and sometimes much longer.

As our daughter gets older and her understanding grows she does sometimes show remorse and say sorry after an incident although, she is unable to articulate why. I'm not sure she understands or even remembers everything that's happened during a meltdown; only that she knows her behaviour wasn't as it should have been or she's seen that she may have accidentally hurt someone.

We have three rules during a panic attack/meltdown no self-harm, no hurting others and no destroying other people's property. So, when she's upset, and in panic phase, one of the first things she now does is head for her sister, as she has learnt that attacking her or trying to trash her sister's room means we intervene to help. We then have three choices, allow the act, which we've agreed we can't, restrain which often results in full meltdown or distract, which is the one she wants; she desperately needs us to help her find a get out, which helps her to save face too.

Being consistently calm during meltdowns, trying not to engage and talk but occasionally offering a few reassuring words ("I'm here when you need me", "love you", "hug", etc.) has proved the most effective strategy in bringing her anxiety down. Talking about what happened after and how we can help for next time is now accepted, providing we have left enough time for her to settle. Talking to soon will set her off again! If she's not ready to talk we don't push it, and have found recently she'll then be more willing to come to us when she feels able.

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 for many adults to do, especially if we seem to be coping with the same triggers and incidents repeatedly, but for our sanity it's essential! Remember, our children do not choose to behave this way; when anxiety is too high they are just unable to control themselves, it's their coping mechanism.

How Do We Cope?

Education - To help us manage her various conditions our daughter has an EHCP and attends a specialist school; she receives both individual and group speech and language therapy at school via NHS therapists and school staff; and we have private occupational therapy sessions.

Developing the Confidence to Parent the PDA Way - I've also set up a local parent PDA support group and have learnt to do what's best for my daughter no matter what anyone witnessing a situation might say. It can be embarrassing and I often wish the ground would swallow me up but I'm learning to have a thick skin in public even if the tears flow privately.

Developing Understanding and Empathy for Our Daughter - Our daughter can't help having PDA, I love her unconditionally and will therefore protect and help her the best I can. It's not an easy journey and there are many twists, turns and loops backwards but we keep pressing forward, pushing boundaries where we can, to try to help develop a happy, beautiful young lady who will have a better control over her emotions and will be able to live comfortably within society.

Taking Time Out - It's also important that we, as parents/carers, remember to take time out both individually, together and with other siblings. We all need to support each other, as living with PDA is a challenge! Siblings often need to change their lives significantly to be able to cope with the demands and/or violence thrown at them; our daughter certainly has and if interested you can read more in my second information sheet "PDA Thoughts – Siblings!".

Summary And Closing Thoughts

There are a couple of important things we realised early on that we must do to keep life as calm as possible for everyone:

- Keep on top of our own personal emotions i.e. we try to stay calm, always, even when we're at our wit's end or just tired
- Develop a very in-direct and non-confrontational style of communication
- Always offer choices and be prepared to negotiate
- Reduce triggers and address any underlying sensory issues
- Be very organised, planning meticulously i.e. timetables must be kept up-to-date and meals planned, in advance, to avoid repetition
- Any outing, whether a 10-minute nip to the shops, a trip to the local park, a visit to the optician or a day with family/friends must be carefully orchestrated with enough time for discussion beforehand to agree calming, distraction and exit strategies needed. Even staying at home and what we'll do requires forethought and a certain amount of planning!

PDA literally takes over from traditional family life, and therefore can cause emotional anxiety within each member of the family, mainly due to constantly watching and waiting for the next incident, then dealing with its ferocity whether positive or negative. PDA is basically an emotional rollercoaster where much of the time we all need to trust our instincts and think quickly on our feet; it's exhausting! If we're too tired or not getting enough of our own emotional support from each other, we can't hope to think or react quickly enough. Our own reactions might then add fuel to a smouldering fire and cause it to flare or ignite! PDA children are undoubtedly challenging when avoiding demands but remember they can also be funny, friendly, incredibly thoughtful and very loving!

Finally, please do remember that these thoughts relate to our own personal circumstances and are strategies that we have found most beneficial to our family. We hope that they may be useful for other families, however we acknowledge that every family will have varying family dynamics and difficulties to deal with that may require alternative approaches depending on the unique needs of the individual with PDA and the unique needs of their families.

If you would like to know more, or would like a copy of “PDA Thoughts – Siblings!”, please contact me via the South Bucks PDA Support Group: PDAGroup@harveys-home.me.uk.

Hilary Harvey – 6th February 2016 (updated)

Resources we have found helpful:

- The PDA Society – Resources Section - <http://www.pdasociety.org.uk/resources>
- The Extreme Demand Avoidance Questionnaire (EDA-Q) - <http://www.pdasociety.org.uk/resources/extreme-demand-avoidance-questionnaire>
- 'Understanding Pathological Demand Avoidance Syndrome in Children' by Phil Christie, Margaret Duncan, Ruth Fidler & Zara Healy
- 'Pathological Demand Avoidance Syndrome: My Daughter is not Naughty' by Jane Sherwin
- 'Children with Pathological demand avoidance syndrome a booklet for brothers and sisters' from the Elizabeth Newson Centre
- 'Can I tell you about pathological demand avoidance syndrome?' by Ruth Fidler & Phil Christie
- 'The Explosive Child' by Ross Greene
- Behavioural Strategy Guide - http://www.thepdaresource.com/files/Behavioural_Strategies.pdf
- The National Autistic Society - <http://www.autism.org.uk/about/what-is/pda.aspx>

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And to you, for taking the time to read this, I hope you found it enlightening!