

## **PDA THOUGHTS - SIBLINGS!**

### **Recognising the challenges caused by PDA, the impact on our daughter and how we try to support her**

#### **Introduction - Recognising the challenges for siblings**

It can be hard for siblings to cope with the variety and ever-changing challenges that present with the Pathological Demand Avoidance (PDA)\* profile of autism and therefore the **emotional support** that they themselves need should not be underestimated.

PDA manifests itself in many different ways but in our personal experience siblings often find the **Jekyll and Hyde** aspects hardest to deal with, particularly when there is physical and aggressive loss of control by the child with PDA (PDAer). One minute their brother or sister is loving and happy, the next they might be kicking and screaming as their anxiety has risen to the extent they have lost all control, which brings on a **panic attack**. These attacks can lead to: the sibling's personal space being invaded; possessions being taken or broken; aggression; violence; verbal abuse; or other such extreme behaviour. For some children however there may be no extreme outbursts just total withdrawal into a quiet safe place, often with little or no communication and possibly, but not always, some form of stimming. Occasionally the child may just withdraw and sleep.

**Obsession** is another difficult issue, as although children with different autism profiles often prefer objects, PDAers regularly focus all their attention on an individual, which can be their sibling. Everything their sibling does, they want to do and often they refuse to leave them alone and give them any space at all. It can be overwhelming and stifling for the recipient.

As we know, trying to remain **calm** at all times is essential but can be hard to do, as is remembering to use **appropriate vocabulary** that isn't threatening or demanding. Siblings are children themselves so it can be hard to constantly think in advance, it's tiring and inevitably easily forgotten especially when caught up in the moment; unfortunately the consequences of not following these strategies will often be long lasting!

There are many instances where a sibling may also need to capitulate and be compliant even if this is seen as unfair. These types of scenarios can lead to **negative feelings** such as being angry; frustrated; scared; unhappy; unloved; bullied; embarrassed etc., as well as fuelling resentment, retaliation or depression.

It's very easy to get caught up looking after our PDAers and inadvertently forget about other members of the family, but the emotional wellbeing of the whole family has to be equally as important.

*\*For more detailed information about the diagnostic criteria and professional understanding of PDA please visit <http://www.autism.org.uk/PDA> or <https://www.pdasociety.org.uk/what-is-PDA>*

## **How does PDA impact our eldest daughter**

Our eldest daughter is 14, she was diagnosed with ASD this year (2019) and also has Severs Disease (a growth disorder) and dyslexia. We have had to acknowledge that life has changed dramatically for her particularly over the last six years since her sister (now age 11) became unable to control her feelings and violence has taken over. Her life is now completely different to many of her peers and it could even be said she has lost some of her childhood, as she has had to grow up quickly to be able to help us cope.

This does make me feel very emotional and sad on occasions, as my daughter can never have a 'normal' carefree life. Since our youngest daughter received her diagnosis of ASD with a profile of PDA in March 2015 we have also had to grieve for the family life that we thought we'd have, but have had to significantly adapt and change.

However, despite the roller-coaster ride we still have, I can say that we've adapted and grown together more as a family, although we also spend more time apart i.e. my eldest goes to ice-skating lessons and spends time with her Dad at the rink while I entertain our youngest often at the cinema or cooking. Then at a different time I might go shopping with our eldest and our PDAer will do something special with Dad, usually the request being Minecraft! It's just about finding the right balance that works for the family and accepting that this is 'your normal'!

What follows is a snapshot of some of the challenges our eldest daughter regularly faces, please remember that not all PDAers will present in this way and some rarely show aggression to others, these are just our personal experiences and thoughts:

### **Careful planning & no spontaneity**

Our eldest often feels like she's walking on eggshells, she's unable to do things at the drop of a hat and family weekends can never be spontaneous and rarely include a trip out or a visit to the cinema or bowling alley unless planned meticulously! Even trips to see family can cause so much anxiety for her sister that these are undoubtedly less frequent than a typical family. Friends are unable to just knock on the door and activities she would like to do often have to be negotiated or carefully suggested to her sister to ensure agreement and compliance.

When on holiday we might ask our eldest for a couple of choices as to what she would like to do on a given day. Then we take these to our youngest and say something like "Mummy and Daddy think these look fun, which one would you like to choose and we can surprise your sister?" If it goes to plan, our eldest gets to do something she wants and our youngest has had the control and choice!

### **Obsession and playtime**

To keep the peace she has to ensure her sister has time with her, often as soon as she gets home from school or when she gets up at the weekend. She is her sister's obsession so she must be prepared to be totally bossed about and play or watch whatever is requested, although a little negotiation can sometimes be used. That's not easy for any child and especially a teenager when children's games no longer feature in their preferred activities and they are expecting to have their own time.

It is hard to be compliant with something you might not want to do and I often find myself getting cross that voices are being raised because her voice tone has got frustrated which has then triggered an incident. I have to remind myself it's not her fault and she is entitled to be frustrated, and it is we as parents who have to try to find a way to negotiate and compromise with her sister instead.

### **Panic attacks / meltdowns**

Our youngest will often target her sister when she is starting to get more anxious, as she knows she'll get our attention. This could be a minor thing like shouting at her or throwing a soft toy/cushion, but equally could quickly develop into pinching, hitting, kicking, biting, etc. If we've been unable to defuse a panic attack or distract her this will often lead to an aggressive violent meltdown and at this point our eldest regularly gets scared and often fears for our safety as well as her own.

When at home, we used to suggest that she gets in her cabin bed, so she's then high up and safe, but the emotional tears used to flow and we couldn't comfort her until we'd resolved the situation with her sister which felt very unfair. Now she's older she retreats to her room herself but usually sits on the floor with her back to the door to stop any entry; she may not cry as much but I can still see the anguish and it still feels unfair!

Our daughter knows we'll protect her and intervene, but if we realise too late there is an issue she can get attacked or a tornado tries to sweep through her room taking her possessions, homework, phone or iPad and often trying to break them.

We've made special high shelves for her to keep things on and changed her drawers and cupboards so it's harder for her sister to gain access, but when the adrenalin flows it's hard pulling her away. We thought about adding locks to doors but decided that the force of entry that can be shown will probably do more harm than good, particularly as she gets bigger.

However, this does mean that during a meltdown we often spend a long time guarding the bedroom door of our eldest, and blocking her sister's path inside or holding the handle to avoid entry. Our eldest can then feel trapped in her own room as it's not safe for her to venture out, as well as having to mentally cope with the constant screaming, (which is often for her help), verbal abuse, kicking of her door and the knowledge that we are taking the brunt of the anger and aggression.

She also has to contend with **shock tactics**. When her sister was younger she might try to wee on her or in her room, grab something and try to put it down the toilet or just spit at her. Now her sister makes a direct path for any homework or technology shouting that she'll destroy it!

Trying to remain calm for us as adults is hard, even harder for our eldest especially when we are helping her sister out of her room and she feels that it is somehow her fault that the explosion has occurred and starts blaming herself. We have often had to say to her that yes, if you had done 'xxx' in a different way it may have had a different outcome, but you didn't deliberately provoke her so you must not blame yourself, it's just that the anxiety took over and she lost control.

When out and about a panic attack or meltdown can initially cause embarrassment to our eldest but this can also lead to anger and frustration as we become trapped wherever we are until the situation is calm; sometimes for several hours. We have had to wait in car parks, on the street, at a friend's house, in play-centres or at clubs on many occasions until things are calm and it is safe to return home. On some occasions it's been necessary to stop the car again as our youngest may have relapsed, having not been as calm as we had thought, and tried to take off her belt or hit her sister.

Patience is something our eldest has had to learn. In addition, she has to remember when not to talk, especially when in the car, as the interruption or whispering, which is usually trying to help, inadvertently causes the situation to escalate. We have to have patience too as it's easy for us to snap especially when we've anticipated what reaction her sister may have but, we must remember, she's just trying to help and be kind!

## **Friends**

Play-dates and sleepovers with friends at home reduced dramatically a few years ago as many couldn't cope with her sister always wanting to play, turning up trying to take something, or just the sudden hitting out, and others have drifted away. Friends can also switch to become the obsession of our youngest, whilst they are in our house, leaving her sibling out in the cold! Fortunately our daughter has several close friends who accept her sister unconditionally and support her. Transitioning to grammar school has also helped as her new friends have just accepted that this is how things are and she may not be able to invite them round as much as she visits them!

We have also helped our daughter's friends to understand more about PDA by providing literature that they read with their family, and subsequently we discuss, offering suggestions of what they could do if they find themselves caught in a controlling and/or aggressive situation. We try to explain that it's best not to retaliate, even verbally, but this can be challenging especially when natural instincts want to take over. Friends have to trust that we will protect them and equally must be prepared to listen and react immediately to our requests; otherwise we might not be able to protect them and keep them safe.

If friends are unable to follow our guidelines, although a difficult decision we won't invite them to our home and instead find alternative meeting places until they are better able to cope.

Where possible we try to have one of her sister's friends around at the same time so she is happy and content, but due to the age gap there is often a time towards the end of the day when her sister's friends have gone, it's not quite bedtime and so her sister will demand to play; at least we can plan for it!

### **Homework and clubs**

Homework can be difficult too, as our youngest doesn't like her sister to stop playing so she can do her work. We have to be creative, sometimes schedule a specific playtime on her timetable, other days negotiate a time and if all else fails remind her that it's her sister's Head teacher who needs the work to be done or we'll all get into trouble if it isn't!

Protecting work is just as important, as during a meltdown this can be torn or scrunched up if left lying around. It's hard to remember sometimes but things have to be put away to keep them safe!

A few years ago, attending music classes and undertaking practice at home could present the same challenges as homework. Surprisingly our youngest used to happily drop her sister off at a class, but on many occasions I had to ask the family of my daughter's music partner to help with transport home as she has refused to leave the house. However, things have changed slightly as our PDAer has chosen to have her own music lessons. It means she's more content about hearing music being played in the home, although as she goes for an earlier lesson she no longer wants to take or collect her sister! A new plan had to be agreed, so my husband comes home early from work every Tuesday and they choose an activity together while I do the music run; at least I now have 30 minutes of me time and the added bonus of being able to chat to my eldest without interruption when we're in the car!

### **Support**

It's really important that help is available and these are some of the ways we support our eldest:

#### **Sharing together**

We have found that it's helped talking openly about her sister's condition and she's also read various publications that have given her a better understanding too. She has learnt the strategies that work and often has more success at defusing a situation than us, using very creative diversion tactics! As she's learnt more about PDA and received support herself she's even found the confidence to write a leaflet to help other siblings in a similar situation.

We've also found that as her understanding of her own ASD has grown during this year she's now helping us to see the differences between one profile of ASD and another!

We do however get frustrated when she forgets the strategies or uses an inappropriate voice tone but it's not her fault, she's still young and has her own challenges. Although she's very mature, we have to remember she is a child herself and we should not expect her to get it right all of the time! We don't!

We have always said we will talk about anything with her and if it's too difficult to talk about we write it down so it's not hidden and the concern doesn't fester. We have also said that if there is ever a time this isn't enough, we will seek assistance from a professional whether this is via Young Carers (see below) or a trained counsellor.

It's important that we offer comfort and a shoulder to cry on after any incident, as she will be as emotionally upset as her sister or indeed us. But the most important thing for us as a family is that we have no secrets, keep talking and trust each other.

### **Young Carers**

Our eldest used to get very angry herself particularly when we might use one set of rules for her and another for her sister, but given time she usually understood why and acknowledged this. With age these difficulties have subsided a little, however not being allowed to choose programmes to watch on the family TV always causes anxiety and frustration as does the invasion of her room and refusal to leave!

To help her understand her emotions and cope with these feelings she is registered as a Young Carer and has received one to one support. She has also attended both a SibShop and anger management course; both courses she said had the added benefit of helping her to understand her sister better too.

Young Carers has been a lifeline. She has made new friends who automatically understand how she feels and there is no judgment, shame or embarrassment surrounding her life. The leaders are caring and understanding, not only to her but to us too. They have shared some lovely ideas to help us talk together openly and also to remember the positives and special times she can share with her sister. There are opportunities to attend Club Nights as well as activity days in the holidays, some of which would be impossible for us to achieve as a family ie. a visit to Thorpe Park.

### **School**

It has also been essential to tell school about what is going on so they can support her too. If they don't know about the challenges she faces they can't begin to understand her mood swings or reactions.

When our eldest transferred to grammar school a few years ago, we also realised how difficult it was for her to open up to new people and share what is going on at home for fear of being judged or left out. However if friends are to visit they have to understand the situation too so we've been finding the right balance together, and her new friends are incredibly accepting.

Fortunately, we also discovered that there are a number of girls in a similar position within her year group so the school is working to support these children together and have established a young carers group within school.

### **Family**

It is incredibly important that as parents we try to have regular 'quality' time with our eldest. This often works best when her sister is asleep (we might invite her to a film or games night) or more recently when her sister has gone to respite care. On other occasions we just have to negotiate time; this includes help for homework or undertake our separate activities as mentioned previously.

We also try to encourage time out with other family members despite this causing additional challenges at home, as it's important she can get to know her extended family and have time out!

### **Sisters**

I remember our daughter saying once, "Why has my sister changed so much so quickly? I feel like she isn't my loving sister any more as she keeps telling me she hates me and wants to kill me." I felt heartbroken, but as parents we felt the same, it did indeed feel like our loving carefree daughter had vanished overnight. We had to try to reassure her that what was being said wasn't actually meant and that it's just the anxiety taking over which leads to shock tactics to provoke a response. However at this point knew we needed to consciously help their relationship develop in a positive direction, as it's so very important to us that our girls are friends as well as loving sisters.

We now try to encourage activities where they can spend time contentedly together and build their relationship with happy memories to draw upon during the harder times. Simple board games, kinetic sand, making slime and cooking seem to be the favourites!

### **The Future**

We do worry what the future will hold and whether our youngest will learn enough coping strategies to be able to live independently by herself. We have also acknowledged that there could come a time when we'll need to question whether our eldest can help take over our responsibilities, if indeed she should (particularly bearing in mind her own diagnosis) or, would want to. It's something our eldest has already questioned but not something that we currently have an answer to....

## **Final Thoughts**

Our eldest rarely says that life is unfair, but it is. She has to put up with: her sister controlling her every move; her room being invaded; being a punch bag; no time for herself; changing friends; having to remember strategies; plus not going abroad or undertaking typically normal activities... I could go on and on.... I am so proud of her. She is strong, resilient, loving, very caring and patient. We love her unconditionally and must remember to tell her more often!!

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 PDAer and the unique needs of their siblings.

## **Additional Information**

For more detailed information, additional resources and strategies relating to PDA please refer to:

The PDA Society <http://www.pdasociety.org.uk> or  
The National Autistic Society <http://www.autism.org.uk/PDA>

I have also written another information sheet based on our own personal experiences:

“PDA Thoughts – For Siblings! Questions and answers about PDA for young people and siblings”

If you would just like to know more, please contact me via the South Bucks PDA Support Group:  
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***Hilary Harvey – revised Nov 2019***