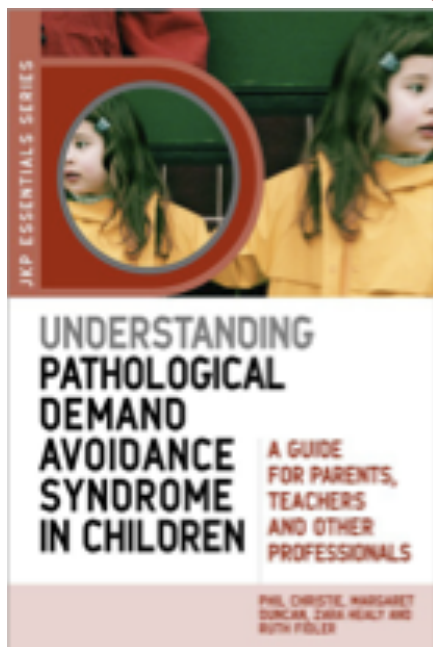




ISSUE 6

PDAContactGroup

www.pdacontact.org.uk



*IN THIS ISSUE:
SUPPORT GROUPS,
YOUTUBE,
ARTICLES
AND MORE.....*



NAS Conference
Manchester 23rd No-
vember 2011

Long awaited and finally released this September by JKP Publishers, in their *Essentials* series, readers of this newsletter are entitled to a **10% discount** (This discount expires 1/10/12) Just enter voucher code **CHRPDA** at the JKP checkout RRP £12.99, ISBN 978-1-84905-074-6). To buy a copy at the discounted price please go to www.jkp.com +44 (0)20 7833 2307

So much has been happening in the world of PDA since the last Newsletter Issue 5 back in 2002! With that in mind this newsletter brings you all the latest events/news and hopefully we can get another one out in Spring. Please e-mail me at margoduncan@googlemail.com with suggestions / articles / letters for the next one.

Run by the National Autistic Society in association with NORSACA. If you missed the very successful Pathological Demand Avoidance Conference in London in January this year there is another chance to hear Phil Christie, Francesca Happé, Ruth Fidler and Judith Gould amongst others talking about PDA. It will be held at the Renaissance City Centre Hotel. To book a place register at www.autism.org.uk/conferences/PDA2011

LOCAL SUPPORT GROUPS

A new ASD/PDA Group is being launched in Winchester (Winchester Autism Group or WAG) on Wednesday 5 October. The group is supported by Hampshire Autistic Society and will run the first Wednesday morning of each month from 10-1130. If you would like to come or would like more information please contact Sam:

07792465452 or Phin:

winchesterautismgroup@gmail.com

Don't forget to log on to the PDA Contact Group forum to network with other parents and find out if there is a local support group near you. If you want to let us know that there is one going on near you (or if you'd like email contact with anyone in your area from the group) please e-mail margoduncan@googlemail.com with all the details and it can be included in the next Newsletter.



PDA Support group in Sheffield runs once a month at the Carers Centre. The

address is 7 Bells Square Sheffield S1 2FY Tel 0114 2728362 Anyone welcome. Free tea, coffee and a shoulder to cry on if needed.



The Maze in Nottingham still holds a drop in service for parents of children with ASDs and in particular PDA.

They are based in Arnold at

28a High Street Arnold, Nottingham NG5 7DZ Tel 01159205800

PDA BLOGS

A few people are blogging about their experiences of PDA. One is a mum called Samantha who tells of daily life with their son with PDA.

"Living with Michael" can be found at alexcparsons.wordpress.com



debz saunders

@**productof1970** London

AutismAdvocate. My son has PDA (Pathological Demand Avoidance). My mission is to open PDA specific schools in the UK & offer counselling to support families & children

PDA ON YOUTUBE

Moose, one of our members has recorded some amazing videos on YouTube for parents and professionals - there are about 8 so far and his first one has over 3800 hits! If you are happier watching rather than reading this is for you. Check him out at

www.youtube.com/user/bluemillicent

"This is absolutely "spot-on"! A very insightful commentary on a complex and exhausting condition for all concerned. Thank you"

"the last video #8 excellent --"pda children are waters troubled by everything and nothing at all" is a very insightful description in my experience--it made me cry -- but the tips are so positive in their aims and that is uplifting."



"We can't tell if your son is demand avoidant. He refuses to co-operate with our assessments"

Moose



If you're more of a facebooker then another of our members has started a facebook group for PDA. It is an open group so you can just add it and then another member of the group will add you.

<http://www.facebook.com/groups/7165353156/>
or search for Pathological demand avoidance (PDA) group.

PARENT VIEW

Rebecca describes the benefits of her daughter's early diagnosis and has a few tips for the important home-school relationship

I first heard about PDA by watching a television programme (*Young, Autistic and Stagestruck Channel 4*) a few months before my daughter's 4th birthday. We had spent the last twelve months living in Ireland and I had been trying to tell professionals there was something 'wrong' with my daughter, but after some assessments we were told she was a bright child, and bright children were challenging. We as a family were referred for psychotherapy (but didn't attend).

After watching the television programme and doing lots of googling, I was convinced our daughter had PDA. Luckily, we had moved back to England and got a new Paediatrician. We were immediately referred on to someone with experience of PDA, and in

November last year, just three months after she turned 4, our daughter was diagnosed with PDA.

We were then in the fortunate position of having a diagnosis a couple of months before she started school in the January. This meant that I could send all the relevant information into school along with her diagnostic report just before she started her visits. She is now in Year One, and although we have had a few glitches, in general her teachers and the SENCO have been fantastic.

Apparently she seems happy at school and is making good academic progress. They do, however, tell me that without her diagnosis they would have approached her differently. She is given lots of choices and she is made to feel in control as much as possible. Whenever any issues come up, they are addressed immediately and I get the impression that nothing is too much trouble. The school and I communicate regularly and they strongly encourage me to get in touch with any issue, big or small. Although times are tough for us, I do have to remind myself how lucky we are that she got her

diagnosis at such an early age, and I can't help but wonder what would be happening now if she were treated like a 'normal' child, pushing the boundaries and being a little 'difficult'.

My main aim right now is to ensure that school is seen as enjoyable for as long as possible, so that it is always somewhere she wants to be. But happenings already this term have shown me that this is perhaps unrealistic. I do worry about the future, the move up to junior school, etc. But I don't allow myself to think about secondary school yet, it is far too scary!!

To anyone reading who thinks PDA may fit their child, I can't stress enough the importance of getting the school on board. Send them as much information as you can, but also produce a short, bullet-pointed sheet showing what works or doesn't work for your child. Sometimes too much information can be overloading and the school may find it helpful to have a brief, to the point, document to show to anyone who may come into contact with your child.

Rebecca (Sheffield)

MOOSE'S MUSE

"Come on, it's time to go now".

Daisy just sat there, her brow furrowed and brown eyes drifted around the room, doing their very best to avoid making contact with mine. I continued to look at her, hoping against hope that we might manage a communication break through and achieve a simple act of compliance.

Nothing!

I inwardly sighed and thought about rephrasing the instruction in an indirect, non-confrontational manner.

I paused, momentarily, for thought and decided on a different approach "Okay, let's see who can get to the car first, last one stinks!". Once again, there was no response. Not a blink or hint of intention, in fact no reaction at all. If I didn't know her better I would have questioned whether she had heard me at all. However, I knew she had 'heard', but was less certain if she was listening or had processed all that I had said. Working on the assumption

that my comments had been digested, we were clearly in the territory of "*computer says no*".

What to do? Do I continue and negotiate or do I use my size to advantage? Well I had an eye on the time and was in no mood for diplomacy, yet I also knew that despite her diminutive size, Daisy was a past master at unarmed combat and would be bound to put up a fight. I was in no mood for that either!

In the end I just picked up the car keys and left the house. Moments later Daisy followed and jumped happily into the car beside me. I was pleased, but not surprised, by the sudden change in mood. This was par for the course and I was simply relieved that we had avoided a public battle of wills leaving the house.

Most importantly we hadn't given the neighbours something to 'tut-tut' about and further fuel village rumours of my parental incompetence and '*that*' wayward family. It was a battle won, but left me feeling no closer to winning the war. In my heart I knew a change in direction was needed, but 'what change' was still an unanswered question.

A mile or two down the road and DD was fast

asleep. I wondered if tiredness had contributed to our difficult morning and hoped she would wake refreshed and in a co-operative mood, ready to disembark at our journeys end without trouble. Glad of the respite from constant fidgeting and whining, I took the opportunity to reflect and review all that I knew of DD Daisy.

Daisy is a mixed bag. She is bright, intelligent and very affectionate. At times she is the light of our lives, bringing fun and happiness to our household, but she can just as easily stretch your patience to the limit and stubbornly need to be in control, be openly defiant or present with challenging behaviour. One moment she will be cuddled up on your lap, the next 'growling' impatience because lunch is taking longer to prepare than she thinks it should. Perhaps none of this is really that abnormal and maybe it is just a stage she is going through? Yet in the back of my mind I mentally check off the similarities with Jacob and the characteristics that are attributable to his PDA.

Daisy is demand avoidant; there is no doubt about that. There is both a refusal and inability to comply and yet there is also a contradictory eagerness to please. She wants to do it, but just can't help being distracted and is obsessive in her pursuit of anything other than what is expected of her.

Empathy? This too is something that she has in a measure. She has a sixth sense if some one is a little blue and can be a ministering angel, yet if she feels she has needs to be met, little will give her cause for concern. Her empathy is therefore conditional and operates providing it does not conflict with her agenda. Once again, not dissimilar to son number two.

Star charts do not work, nor does the promise of a reward to be earned for tomorrow. Everything is in the here and now. We haven't tried pocket money or marbles in a jar, but are certain that these motivators would not work either. She can be delighted with praise, but will often act over the top. It also would not be the first time she has shredded a sheet of A4 or ripped up a reading book.

Changeability of mood? I think I can safely say 'yes' to that.

Lack of sense of self and/or identity? Daisy enjoys playing with her siblings and peers, yet is most comfortable with adults. She has quite an obsessive relationship with me, and has been known to cry if I leave the room. She is strangely independent and dependant at the same time, highly sociable but with a bond to me that is somewhat different in quality to an attachment disorder. She definitely does not see the need for different rules for her to other members of the family.

Developmental delay? I am uncertain about this. Potty training was a little hit and miss to start with and we did wonder if we would ever get there. It seems that many things take a while to sink in, but then she advances at a pace of knots. Perhaps her development would be best described as 'lurchy' rather than delayed.

Role play? not as such, but is quite imaginative with her games and certainly seems to regard her soft toys as real animals. Worryingly she even appears to have developed a crush on her favourite com-

panion, whom we have nicknamed '*luv bunny*'.

As I pondered these traits I realised that there were many more likenesses to Jacob, yet somehow something was different. I did not want to repeat the mistakes we had made with him, but neither did I want to label Daisy prematurely. I did not want to miss a problem, but had no desire to create one either. In the end I resolved to adopt an over arching strategy that would either remedy the difficulties or expose the problems for what they really were. Pretty much a kill or cure approach, but at least we would know what we were up against.

I decided to revisit the traditional behavioural route; measured discipline dealt with a determined hand and general no nonsense stance. I didn't exactly have boot camp in mind, but more the firm, but fair, discipline I had received as a child. It had worked for me and equally well with our eldest son. It would be an honest, good old-fashioned mix of rules, rewards, sanctions and enforcement. All of this, of course, administered with love.

I am now into a third month of my new adoptive strategies and all has worked remarkably well. Behaviour Support Services would be proud of me. I have stuck to my guns on everything and have applied all the lessons of conventional wisdom that seemed so inappropriate for Jacob. Yes, I have needed to modify some to suit Daisy's character, but by and large my faith has been restored. Once again I am a believer that dedication, persistence and even the naughty step can work. Daisy is living proof. She has been transformed. Traditional behavioural strategies really do work.

Now some of you who know me may not believe what you have just read. Has Moose gone mad, has he defected to the darker side? No, that is not the case.

I have always said that it is a case of 'horses for courses' and the right methods must be applied to the right case. Besides that, Jacob is a 12-year-old boy with PDA and DD Daisy, (if you haven't already guessed), is a neurotypical, 4month black Labrador puppy, a Dear Dog indeed!

Moose is a regular contributor on the PDA Contact forum <http://ccgi.pdacontact.org.uk/forum> an online community forum for parents and professionals to discuss all things PDA



This Newsletter is produced by members of the PDA Contact Group. We are not a charity (yet) just a parent-run support group helping each other, providing information and increasing the awareness of PDA.

Our website address is

www.pdacontact.org.uk

Our online forum is

<http://ccgi.pdacontact.org.uk/forum>

If you'd like to e-mail us with any ideas or articles do so at

margoduncan@googlemail.com