

# **PDA** — Pathological Demand Avoidance

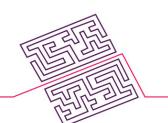
From diagnosis to supporting...



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N.B look out for 2017 – the National Autistic Society – Pathological Demand Avoidance Conference



# Pathological Demand Avoidance

hursday 6 October 2016, National Conterence Centre, Birmingham

Providing professionals and parents with clearer understanding of the diagnostic criteria, plus essential strategies for education, management and communication.



www.autism.org.uk/conferences/PDA2016

The National Autistic Society

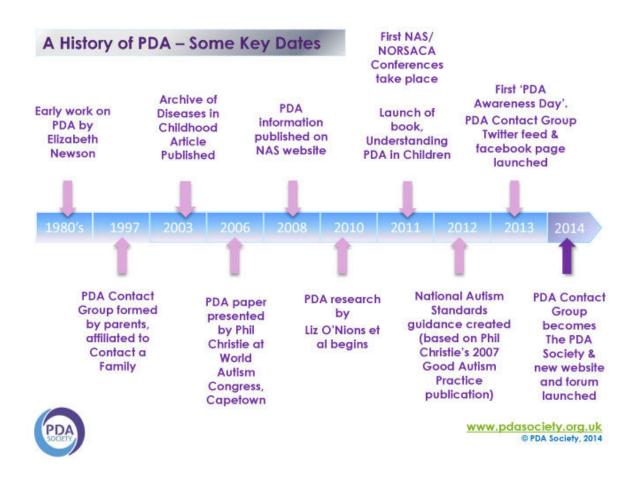
# History of Pathological Demand Avoidance by the PDA society

PDA is increasingly recognised as part of the autism spectrum however it is not a condition in its own right as part of the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders)

PDA was first described by Elizabeth Newson during the 1980s as a pervasive developmental disorder distinct from autism. Since then PDA is becoming increasingly recognised as part of the autistic spectrum.

The National Autistic Society in 2015 formally recognised PDA as part of the Autistic 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." – NAS (National Autistic Society)



# What is Pathological Demand Avoidance?

People with Pathological Demand Avoidance Syndrome (PDA) will avoid demands made by others, **due to their high anxiety levels** when they feel that they are not in control.

They present with extreme behaviours related specifically to the demands made by others.

PDA should really be considered under the Mental Health remit

They will avoid both Hard and Soft demands I.e. you must.... and can we do....

It is distinct from Autism – This occurred because many children and young people were non-responsive to Autistic strategies, structure and routines.

PDA is a lifelong disability and has varying degrees depending on how much that person has learnt better coping strategies or developed abilities to manage. Threshold for accepting social demands can fluctuate depending on different factors i.e. additional strategies being used.

Many children avoid demands to some extent, but children with PDA do so to a far greater level than is considered usual. This is why it is called pathological.

There is a belief that PDA is genetically based but at the moment no-one has identified a specific gene/s to make it genetic.

#### Difference between ASD and PDA

ASD	PDA
Difficulties with Social Communication Difficulties with Social Interaction Rigid thought patterns Sensory Processing Difficulties Separate mental health of anxiety disorders	Better imaginative play Better eye contact Trouble with fact vs. Fiction Avoid demands Don't understand social rules High emotional anxiety (ASD has some anxiety but not to extent of PDA) Very Sociable Do not respond to routines

Boys are more likely to be diagnosed with Pathological Demand Avoidance at a ratio of 1:4 this is because girls tend to have inbuilt skills and are socially manipulative.

# How does PDA present in children, young people and adults?

They will generally have better social communication and interaction skills but they will still have difficulties due to the need to be in **control**.

They will obsessively resist ordinary demands such as getting up/brushing hair/every day demands

There are four types of demand they will resist:

- > Direct
- Subtle (sugar coated demand)
- Silent Demand i.e. talking through rules (indication/actions)
- Self-imposed demands anxiety stops them they simply can't then do the task

Socially manipulative i.e. they will try and avoid situations by doing certain actions that will cause a move away from that situation.

Appearing sociable **but lacking depth in understanding** – this can be linked to ASD.

Excessive mood swings which switch suddenly, can be impulsive and always led by the need to control

Comfortable in role play/pretending – emphasis is away from them (if you have an Autistic Spectrum Disorder you tend to avoid this)

Language delay – often good degree of 'catch up' – to explain this we need to look at language delay in relation to Autism, Aspergers and PDA

- Autism is a delay in development of language
- Aspergers have no delay in the acquisition of language
- PDA initial delay but catch up rapidly (often sometimes overnight)

Obsessive Behaviour – focus on people rather than things – i.e. a particular person

Neurological involvement – might be linked to epilepsy/absences

### How do children, young people and Adults present "Avoidance" Strategies?

- **Distraction** they will often look out of the windows or change the subject
- ♣ Acknowledge the demand but exclude themselves –

I.e. I'm sorry I can't "Mum wouldn't like me to do X" "Dog ate my homework"

They will tend to blame someone else and not take ownership of their actions. There is an overlap with ASD as they will often not recognise there are consequences of actions.

**4** Physical incapacitation – hiding under the table/ self isolating/ absconding

Examples - often accompanied by an explanation such as "my legs don't work" or "my hands are made of lava")

- They will often withdraw into fantasy i.e. my teddy doesn't like this came
  they also struggle to recognise fantasy from fiction
- Reduce meaningful conversations through mimicking, refusing to speak – this crossovers with ASD

This can be linked to Echolalia which is either:-

- Repetition of what has been overheard
- Mimicking what has been heard

Can be used to remove them from a situation causing anxiety

Can be a self-calming strategy

**Understs** – Considered to be a behavioural response and is linked to ASD

This could be screaming, hitting, kicking and is considered an anxiety response, best described as a 'panic attack'.

### Further exploring aspects of Pathological Demand Avoidance and signs

In Early Years PDA presents as

- Passive/placid, won't reach for toys/drop them
- More actively resistant as expectations increase
- Difficulties highlighted when in group settings
- No significant difficulties in development, they will reach all their physical milestones
- When playing they will try and control the situation by ensuring games are played by their rules

As they get older they continue to resist

- High degree of pressure from every day demands
- Any suggestions perceived as demand

Indirect – make them think it's their suggestion Two choices  $\rightarrow$  give them the illusion of control Word things so that it's their idea

- Anxiety about conforming to social demands they struggle to comprehend and process social rules such as queuing
- Inability to accept situations

Many children and young people with PDA will struggle to accept reason behind demands – such as the demand "you can't touch that, it's hot". As a result children and young people often act impulsively as they do not accept the demands placed on them by others.

# national autism standards

Supported by: Department for Education

# The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice

Phil Christie, UK

Taken from the Good Autism Practice Journal published by BILD, 2007, by kind permission

### Address for correspondence:

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Acknowledgements: Special acknowledgement should go to Elizabeth Newson for her pioneering work in this area. Thanks are also due to staff at Sutherland House School and the parents who have contributed to this paper.

#### **Editorial comment**

Phil Christie is currently the Director of Children's Services within the Nottinghamshire Regional Society for Children and Adults with Autism (NoRSACA) and has been Principal of a specialist school for children with autism for over 25 years. This paper was first presented at the World Autism Congress held in Cape Town, South Africa in 2006. It provides details on a syndrome which was identified over a long period of time by Professor Elizabeth Newson, often in work done jointly with this author, Phil Christie. In the many diagnostic assessments conducted at the Child Development Research Unit based at the University of Nottingham, she found there were children referred with a possible diagnosis of autism who did not seem typical in that they shared some of the features but had other very different behaviours and characteristics. There were also more girls affected than boys. After several years of careful note-taking and interviews with parents, she felt that there was sufficient evidence to create a new syndrome or diagnostic description within the category of Pervasive Developmental Disorders. She named this Pathological Demand Avoidance syndrome and first brought it to public attention in 1980's. Since that time, there has been much debate between professionals as to whether this is indeed a separate condition or whether the behaviours found in PDA can be explained within other disorders such as attachment disorder or personality disorder or a female form of autism. Readers of this paper can send their thoughts and personal experiences to the author or the Editors of GAP to add to the debate.

This document gives practioners a good insight into PDA. We have summarised some of the key aspects of this paper below. I have also added the link here in case you wished to read it in more depth

http://www.aettraininghubs.org.uk/wp-content/uploads/2012/05/5.2-strategies-forteaching-pupils-with-PDA.pdf



On the surface the child or young person with PDA will come across as socially able but can use this to manipulate. They might also have a lack of social indentify.

The types of strategies that might be used to manipulate people are:

- Distraction
- Giving excuses
- Delaying i.e. have you seen.... or I just need to.....
- Saying they can't a sign that they are anxious about what will happen if they do the task
- Arguing
- Suggesting alternatives
- Withdrawing into fantasy

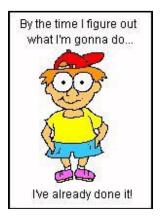
They can be people orientated and come across charming. This means that children and young people with PDA will often have social appropriateness and can use this to manipulate situations.

They can have good eye contact and body language. This is different to those with an Autistic Spectrum Disorder.

- ✤ Social approaches/responses are unsubtle
- They can be unsure of the level of response they will get from someone else
- Can be overpowering in response i.e. using I want.
- They can come across rude
- **4** They will often be ambiguous when responding to conversation
- They will often destruct work if praises
- They can often empathise at intellectual level rather than emotional level they might not present with an emotional respond. They might understand but still not act accordingly
- ✤ They can often understand emotional rules but have no motivation to apply them
- They will often have difficulty in developing a 'personal identity'
- They might fail to identify with other children
- They might not understand unwritten social boundaries
- Have a lack of pride/embarrassment
- Uninhibited i.e. might flash in the middle of a public place (n.b this can create a level of vulnerability)
- They might struggle to accept social obligations or take responsibility for their own actions

They will often struggle to have relationships with their peers if a child or young person. They will prefer adult interaction and conversation

They will often by shocked and confused by the behaviours of others. They might also blame others if things go wrong.



### Children and young people with PDA will often present as impulsive



- They are led by the need to control
- They can change their mood rapidly
- They can find it difficult to regulate emotions
- They can be unpredictable and wearing to be with



Parents describe this as the following light on and off"

"it's like switching a

## Children and young people with PDA are often comfortable in role play



This can be different to those with an Autistic Spectrum

Disorder. They can mimic, take on roles, repeating and re-enacting. This can be incorporated into avoidance tactics for example "I can't pick it up...I'm a tractor and tractors don't have hands".

A further example is children who behave as if they were teachers to other children

They develop around fascination and this can be pursued obsessively.



Children and young people with PDA are often delayed in the development of language

- ✤ They can have a delay in some aspects of their speech/language development
- This becomes part of their general passivity
- There is often a sudden/striking degree of catch-up with their peers
- They can make fluent use of eye contact
- + They have less difficulties in pragmatics of language (non-verbal forms of language)
- They are good at expressing themselves but still struggle with the understanding and processing

#### Children and young people with PDA often display obsessive behaviour



They can have special interests (this is a similar traits

of those with an Autistic Spectrum Disorder). Children and young people will often become fixated on specific individuals rather than objects. Demand avoidant behaviour usually has an obsessive feel; other demands tend to be social and can result in blame and harassment, which can cause difficulty for peer relationships in school.



# Children and young people with PDA often have a Neurological involvement

Crawling is late or absent in more than half these children and other milestones can be delayed. Many other physical milestones are delayed e.g. sitting. They often exhibit clumsiness or physical awkwardness. They might sometimes exhibit "fitting" in situations of attention. PDA is induced by anxiety and demands based.

#### Taken from Page 7-8 of the aforementioned guidelines

#### Key Characteristics as a learner

#### Children with PDA are more likely to end up as a 'school refuser'

"The overriding state of the child's approach to school and learning is one of anxiety, which for a number of children impacts on their willingness to come to school in the first place (the ultimate avoidance). This requires detailed planning and negotiation with parents, the child and those involved with the transport. Unsurprisingly, this anxiety is largely driven by the child's perception of demands or potential demands, being faced with failure and not being in control."

A child or young person with PDA will have a combination of the following

#### Emotional Wellbeing

- A very poor sense of self-esteem resulting in children expressing that they can't do something or won't like is as a 'first response'
- Very poor emotional regulation prone to mood swings. The child or young person's level of tolerance is mood-related

#### **Learning**

- An expressed desire to be equal or better than others, but not seeing it as necessary to put in the effort required.
- Ambivalence about success and enjoyment i.e. a child that destroys their work on completion when praised by a teacher
- Lack of permanence and transfer of learning and experience there can be sudden and dramatic setbacks after relatively prolonged periods of settled behaviour and progress

#### **Friendships**

- They can desire friendships but inadvertently sabotage them as well this links with the need for control, manipulative behaviours, mediating or refereeing others interactions.
- The child may also blame and victimise other children for things that have gone wrong, even though this is often as a result of their own behaviour
- They can hold grudges for prolonged periods of time and plan retribution

#### **Behaviour**

- Explosive Behaviour or aggression can be shown
- The child or young person may express threatening language and shocking language such as swearing
- There is a need to be in control
- There is a variability in behaviour

• Extensive involvement in fantasy and role play in a way that cuts off the child and leads to some of them feeling that they have features of those they mimic or identify with. This can be problematic (eg a feeling of being 'omnipotent' when identification is with cartoon characters, superheroes etc).

#### PDA in Norfolk

#### Extreme Demand Avoidant Questionnaire

In Norfolk and Suffolk ASD Helping Hands Adviser-Advocates are able to complete the Extreme Demand Avoidant Questionnaire and produce a report which can then be used to investigate PDA further if the score indicate. We do not give out the scoring so as to ensure the scoring is independent and not skewed. This means are reports have more credibility with Judy Eaton than if a parent completes it on their own. Once the report is compiled it becomes the property of the parents and you can then do with it as you wish.

The 'Extreme Demand Avoidance Questionnaire' (EDA-Q) is a measure designed to quantify traits of extreme/'pathological' demand avoidance (PDA) in children aged 5-17, on the basis of parent or teacher-report. The questionnaire was developed to make sure that PDA traits were being measured in a consistent way for research purposes.

The questionnaire was designed with input from clinicians working in a variety of settings in the UK who had experience of PDA. A preliminary validation study was conducted, in which parents reported on their child's behaviours and the diagnoses they had received, as well as completing the new questionnaire. Scores on the EDA-Q were significantly higher in children whose parents reported that they had been clinically identified as having PDA than in all comparison groups, including children reported to have ASD with disruptive behaviour.

They ran analyses to find a cut-off score that would best differentiate PDA from comparison groups. Different risk cut-offs were required for older and younger age groups. A cut-off score of 50 was appropriate for ages 5-11 years and 45 for 12-17 years. These cut-offs identified individuals at risk of having a profile consistent with PDA. However, a comprehensive assessment by an experienced clinician, including a detailed developmental history, observation of the child, and information from a range of sources is required when considering whether a child displays PDA features. It is possible for an individual to be rated by parents or teachers as having behaviours associated with PDA but, after a full assessment, for a different clinical description to be deemed more appropriate.

In particular, current research on PDA has focused on individuals who display both PDA features and autism spectrum disorder. This work suggests that PDA features are dimensional within the autism spectrum, and that taking them into account in a diagnostic formulation can provide a more accurate description of the child's behaviour. Studying individuals with this presentation will allow us to identify more tailored behavioural management approaches. However, less attention has been paid to the overlaps between PDA features and other conditions besides ASD. When conditions are defined by lists of behavioural features there will be interconnections and overlaps. More research is needed to explore these possible overlaps.

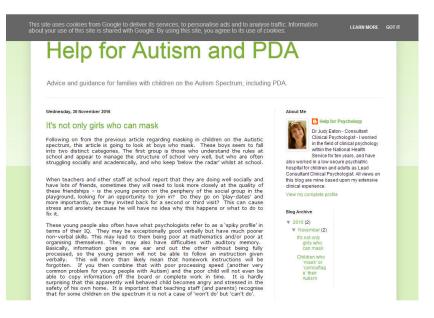
#### **Diagnosing PDA**

In Norfolk the Community Paediatricians are reluctant to diagnose PDA on the NHS. As an organisation we have no choice but to signpost people to private organisations that can assist with PDA investigations and potential diagnosis.

<u>www.help4psychology.co.uk</u> is run by Judy Eaton and her team and is the only place in Norfolk that manages PDA



Judy Eaton has also recently started a blog to assist people who think there child/young person has PDA – <u>https://help4psychology.blogspot.co.uk/</u>



There is also a new Parents Support Group for PDA in Norwich February 1st 2017, 10.30 - 12.30 The Conference Room @ Help for Psychology The Grange NR6 7NF please contact SENsational families on facebook for more information https://www.facebook.com/groups/1501254960201776/?fref=nf

#### PDA resources



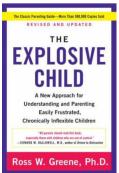
This book is wildly used by advisor-advocates at ASD Helping Hands -<u>http://www.pdasociety.org.uk/professionals/awareness-matters-booklet</u> only use if you have already had an EQA completed by someone independently (or ASD Helping Hands) as includes this in the booklet and also gives the scoring – if used we cannot give an independent report



Written by Ruth Fidler and Phil Christie

This book is part of the Part of the Can I tell you about ...? Series

In this illustrated guide Issy invites readers to learn about PDA, a part of the autism spectrum, from her perspective, helping them to understand how it causes her to find simple, everyday demands very stressful. Issy tells readers (aged 7 upwards) about all the ways she can be helped and supported by those around her.



'The Explosive Child' Written by Ross W.Greene - Although not written specifically about PDA, this book offers some really useful management strategies for 'chronically inflexible children'.

You also have the leading website for PDA - <u>http://www.pdasociety.org.uk/</u> for many more resources

#### PDA Training for Parents/Professionals

Managing your Child with PDA run by help4psychology

This one day course, delivered by Dr Judy Eaton, is aimed at parents, and grandparents, who have (or suspect they have) a child with Pathological Demand Avoidance (PDA). The course will provide information on the key features of PDA, how PDA differs from other disorders such as Oppositional Defiance Disorder and Conduct Disorder and how to access a diagnosis and support. It will also address triggers for behavioural 'meltdowns' and how to manage them when they do occur. We will also look at the impact of having a child with PDA on partners and siblings. Finally the course covers a brief look at PDA in adolescence and mental health issues in young people with PDA. The course is run in an informal and supportive manner and provides plenty of opportunity for discussion and sharing of ideas and experiences.

Course outline:

- ★ Introduction
- ★ What is PDA?
- ★ Signs of PDA
- ★ How PDA differs from other disorders
- ★ Getting a diagnosis
- ★ Accessing support
- ★ The impact of PDA upon partners and siblings
- \* 'The Solihull Approach' Containment, Reciprocity, and Behaviour Management
- ★ Looking at triggers for 'meltdowns'
- ★ Managing 'meltdowns'
- ★ PDA and adolescence
- ★ PDA and mental health issues

#### Or

Managing the child with PDA in the school environment run by help4psychology

This one day course is aimed at classroom teachers, SENCOs, teaching assistants, support workers and lunch-time staff. It provides an overview of the key features of Pathological Demand Avoidance (PDA), and explains how PDA differs from other disorders such as Oppositional Defiance Disorder and Conduct Disorder. We discuss how the school environment can impact upon a child with PDA and offer suggestions for maximising learning opportunities for these children. How to recognise triggers for behavioural 'meltdowns', together with their management, is also included. Promoting positive relationships with parents and tackling the issue of exclusion is covered along with discussion about EHCP's. Finally we discuss PDA and adolescence and PDA and mental health issues. The whole course is run in an informal manner and provides ample opportunity for discussion, questions and sharing of ideas.

Course outline:

- ★ Introduction
- ★ What is PDA?
- ★ Signs of PDA
- ★ How PDA differs from other disorders
- ★ PDA and the school environment
- ★ The child with PDA as a learner
- ★ Issues for teachers and TA's (EHCP and managing exclusion)
- ★ Building positive relationships with parents
- \* 'The Solihull Approach' Containment, Reciprocity, and Behaviour Management
- ★ Recognising triggers and managing 'meltdowns' in the classroom
- ★ PDA and adolescence
- ✤ PDA and mental health issues

#### Keep in touch

Find out more about how we can help you and your family, and how you can get involved with our work. Just fill in this form and post it back to us

Title First Name Surname Address (line 1) Address (line 2) Address (line 3) Town Postcode Telephone number Mobile number Email address

ASD Helping Hands would like to keep you informed about our services, upcoming news, events and fundraising activities. We will look after your data as set out in our privacy and data protection policy.

□ If you prefer not to receive information by post, please tick this box

□ If you prefer not to receive information by telephone, please tick this box

□ We'd like to keep in touch by email, if you are happy with this, please write your email address in the space provided above

What is the date of birth of the person you are contacting us about?



#### Please return this form to:

Room 219 Breckland Business Centre St Withburga Lane Dereham Norfolk NR19 1FD We would like to tailor our communication with you to ensure they are relevant to your interests.

What is your connection with autism? (Please tick all that apply)

□ I am autistic

□ I am the parent/carer of someone on the Autistic Spectrum

□ Someone in my family is diagnosed with autism

□ I know someone who's autistic

□ I am a professional working in the field of autism

I have another connection with autism Please Specify\_\_\_\_\_\_

□ I have no connection with Autism

"ASD Helping Hands will support all service users affected by an Autistic Spectrum Disorder (ASD) regardless of age or what stage of life they are at. We aim to offer guidance, practical advice and support whether you are personally affected or you are an associated family member, carer, friend or professional. We will actively champion the rights of all people affected by ASD's and aim to make a positive difference to their lives while delivering a service that is accessible, reliable and trustworthy."

The organisation is for all affected by the Autistic Spectrum, this covers a wide variety of difficulties. We believe that all families and individuals have the right to good quality information, support and guidance in order to promote empowerment to allow positive choices to be made, enabling access to the same opportunities as everybody.

Currently working across Norfolk and Suffolk

#### **ASD Helping Hands**

219 Breckland Business Centre St Withburga Lane Dereham Norfolk NR19 1FD

Autism Helpline: 01362 853018 Email: <u>asdhelpinghands@gmail.com</u> Website: www.asdhelpinghands.org.uk

> ASD Helping Hands is a voluntary organisation and relies on voluntary income to support its work, including the development of resources like this one for parents and carers

> > ©ASD Helping Hands 2017