

# PDA Guidance

*Navigating the PDA Journey*



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## Does My Child Present with PDA Profile of ASD?

Posted on [July 27, 2017](#)

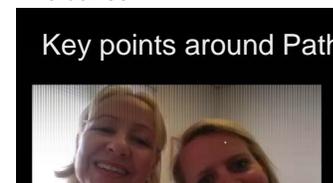
**Introduction** – This is a general guide for parents to help them establish if their child is presenting with a typical presentation of [an autism spectrum disorder \(ASD\)](#) such as [Asperger’s Syndrome](#) or [Pathological Demand Avoidant \(PDA\)](#), which is a different profile of autism, seen in some individuals on the spectrum. **N.B. This guide is by no means exhaustive and there will always be exceptions to the rule.**

ASD is a spectrum that is complex, overlapping and can affect individuals to varying degrees. Therefore, it can sometimes be very difficult to differentiate between the different profiles and some children may have an overlapping profile, where features of two distinct profiles such as Asperger’s and PDA or classic autism and PDA are overlapping without either being distinct.

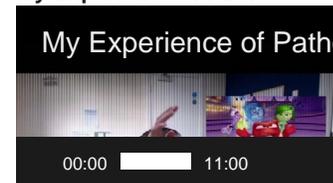
**Please note that where a child fits on the spectrum can only be accurately and officially determined following an assessment by an experienced multi-disciplinary ASD diagnostic team.** But, because awareness, understanding and acceptance of the validity of the PDA profile of ASD remains a contentious issue among many professionals, the diagnostic pathway for these children and their families is often extremely stressful and, for some, unobtainable if their child has an atypical ASD profile, such as PDA. If we also factor in the incredibly long waiting times for appointments and assessments, which can in many cases take years, parents and others involved with a child will often need to develop an understanding of the child’s difficulties and to build a framework of suitable strategies a long time before they are in receipt of an official diagnosis.

*PDA is already a very real clinical problem, not just in the United Kingdom, but across the planet. Intervention and treatment currently rest almost exclusively on*

### Key Points About Pathological Demand Avoidance



### My Experience of PDA



### Categories

- 1. Assessment & Diagnosis
  - 1. Does my child present with the PDA profile of ASD
  - 2. Differences between PDA and ODD
  - 3. Differences between PDA and RAD
  - 4. Importance of [Diagnosis](#)
  - 5. Diagnostic pathway
  - 6. Refining an ASD diagnosis to reflect PDA
  - 7. Requesting an Out of Area Referral
  - 9. Professionals who diagnose PDA
- 2. Education
  - a. Requesting Support in School
  - b. Requesting an EHC assessment
  - c. EHC Assessment & EHC Plan
  - d. School Refusal

*guesswork, clinical experience and trial and error. It is one of the most 'difficult-to-treat' constellations of problems in the whole of child and adolescent psychiatry. Strategies developed for ASD, ODD or ADHD are often ineffective and parents, teachers and clinicians may be driven half crazy by the child's stubborn refusal to cooperate and by avoidant, manipulative and exhibitionist-style shocking behaviours. [Christopher Gillberg, Commentary: PDA – public display of affection or pathological demand avoidance? – reflections on O'Nions et al. \(2014\)](#)*

Therefore, distinguishing which of the profiles of ASD appears to be most applicable for the child, prior to an official diagnosis, is often required and necessary for those involved with the child. While it is accepted that each child is individual and will require an individually tailored framework of strategies, which should not rely on any particular profile of ASD or set of standardised strategies alone, identifying which profile of ASD most suitably explains a child's difficulties and presentation can often be a good signpost and starting point in beginning this process.

### Caveat

I am not a professional and so this information is collated from various credible sources combined with my own personal experiences, both as a parent of two children on the spectrum (one child diagnosed with Asperger's and one child diagnosed with PDA) and from my many years of involvement supporting other parents.

## Quick and Easy Checklist

[Pathological Demand Avoidance](#) (PDA) is one of the profiles of an Autism Spectrum Disorder (ASD) that is seen in some individuals on the autism spectrum. The importance of recognising if a child has ASD with a profile of PDA is because this has implications for understanding, support and intervention.

The following information may be helpful to assist parents in further exploring the similarities and the differences between a typical presentation of ASD and the PDA profile of ASD.

1. Children with PDA present with autistic traits which may be typical, atypical or a mix of the two. But, autistic features do need to be present for a diagnosis of ASD with a profile of PDA.
2. The **extreme** demand avoidance exhibited by the individual with PDA would have a different quality and nature to it than the demand avoidance that is seen in some individuals with a more typical presentation of ASD. The use of ASD strategies should help to reduce the level of demand avoidance exhibited by those with a more traditional profile of ASD. But, for those with the PDA profile an entirely different emphasis is required and these strategies, while making life more manageable, may not actually reduce the inherent demand avoidance.
3. In addition to their ASD traits, individuals with the PDA profile of ASD also present with a unique cluster of symptoms, some of which may be seen in other individuals on the spectrum, but an individual with the PDA profile of ASD would need to display many of these key features and not just one or two of them for a diagnosis of ASD with a PDA profile.

- e. Alternative Provision SEN
- f. Home Education delivered by the LA
- g. Home Education Delivered by Parents
- h. Child Masks Difficulties in School
- i. Rewards and Consequences don't work
- 3. Strategies, Understanding, Resources, Discussion and More
  - [Beginning to Build a Framework of Strategies for Children](#)
  - [Beginning your journey with PDA](#)
  - [Child Masks Difficulties](#)
  - [Meltdowns](#)
  - [mental health issues](#)
  - [Obsessions](#)
  - [PDA from the Perspectives of the Person with PDA](#)
  - [Personal hygiene](#)
  - [Rewards and Consequences do not work](#)
  - [Sensory Issues](#)
  - [Sexualised Behaviour](#)
  - [Siblings](#)
  - [Sleep](#)
  - [Social Anxiety and Isolation](#)
  - [Stealing, lying and practical jokes](#)
  - [Transitions](#)
  - [What is a Demand and the Cycle of Avoidance](#)
- 4. Support Groups, Training and Workshops
- 5. Campaigning for PDA Awareness
- 6. The Reality of Navigating Services
- 7. Do you live outside of the UK?
- [Uncategorized](#)

### Blogroll

- [1. The PDA Society](#) The Official Charity for Pathological Demand Avoidance Syndrome
- [2. The National Autistic Society / PDA](#) The National Autistic Society have an increasing bank of information about PDA
- [3. PDA Resource Page](#) A resource page full of everything you need to know about PDA
- [WordPress.com Blog](#)

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## Resources

The National Institute for Care & Excellence (NICE) pathways provide an extensive list of features and behaviours, that can be indicative of a child with ASD, which you can download from their website [recognising possible autism in children and young people](#).

The PDA Society have also produced a leaflet which offers a quick guide to [recognising ASD in the early years](#) and the different profiles that children may present with.

The '[Extreme Demand Avoidance](#)' questionnaire (EDAQ) questionnaire was designed by Liz O'Nions et al to identify individuals with an elevated risk of having PDA for research purposes only. It is not a validated diagnostic tool and should therefore be used as a guide only to identify possible PDA traits in individuals, for the purpose of highlighting the need for further evaluation which should be based on a multidisciplinary assessment by a team of experienced professionals.

Part one and two of the PDA Society's webinars '[Understanding PDA](#)'

If you would like to read about these points in more depth, I have provided a more detailed explanation below

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## 1. Difficulties Shared by all Individuals on the Autism Spectrum

**First and foremost, a child with the PDA profile of ASD will present with similar difficulties in the same areas as other children with a more typical presentation of ASD.** It is also important to remember that ASD is dimensional and will affect different individuals to different degrees and in varying ways.

All children on the autism spectrum, including those with a profile of PDA, will have difficulties in the following areas

- Social interaction
- Social communication
- Restrictive and repetitive patterns of behaviour, activities and interests

### The atypical Presentation of PDA

However, it is worth noting that some of the difficulties shared by those on the spectrum may not be immediately evident to others, for those children whose ASD is more accurately described by the PDA profile, due to what is often described as an atypical ASD profile. Some of these differences are described in more detail below.

### Social interaction and communication

Children with PDA can appear to have better social understanding and communication skills than others on the spectrum, described by Newson as 'surface sociability but lacking in depth'.

Also, these children are often able to further conceal these difficulties by copying, which is a form of (social echolalia), what they perceive to be the correct social initiations and responses from those around them.

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This surface sociability possibly resulting from social echolalia, combined with what can often be very challenging behaviour, can hide very real difficulties in this area. Therefore, scratching beneath the surface may be required when identifying these areas of difficulty, some of which are listed below.

- Unaware of their social hierarchy in society i.e. thinks that they are an adult and doesn't automatically confer to their natural place in social hierarchy **e.g. may act like a teacher when playing with peers**
- Dominating and controlling in social interactions with others, including peers **e.g. they will often control the direction of play and are unable to allow others to deviate from this direction or have any input**
- Can be overfamiliar with others too soon, when it is not socially appropriate to do so and at inappropriate times, **e.g. sitting on a teacher's knee during class or hugging someone of authority that they have just met**
- May display behaviour that shocks those around them without understanding how this will affect how others view them, which can cause real difficulties with friendships and relationships with adults **e.g. lashing out at peers, removing their clothes in public and arguing with adults in authority**
- Will insist that other children follow rules but don't understand why they should follow the same rules as others **e.g. may tell on another child for not wearing their coat outside and insist that the other child should have to follow the rule, but then refuse to put their own coat on**
- Dominates conversations and will repeatedly turn the conversation around to their own topic of interest **e.g. only engaging in conversation if they are able to dominate the topic. If this isn't possible they may disengage from the conversation or seek to regain control by repeatedly talking over others.**
- Although expressive language can be fluent and articulate their receptive language may include difficulties with processing speed, accurately interpreting what has been said to them or filling in the blanks of the unspoken word **e.g. may ignore requests due to lack of understanding of what is required, may only process certain words from a sentence leading to misunderstandings and may not be able to follow instructions that are vague and lacking in detail.**
- Language can appear unusual in that phrases and words used may appear to be copied from others, this can seem bizarre when a very young child is using language that you would usually expect to hear from an adult **e.g. may say to their peers "you wouldn't behave like this at home and so I don't expect you to behave like this at school"**
- Over sensitive to intonation of voice i.e. always feeling that they are being told off or shouted at **e.g. asking a child to turn down the TV in anything other than the most neutral tone can result in them shouting back "stop yelling at me"**

### Masking

Difficulties reported by parents, such as challenging behaviour, signs of anxiety and the child's refusal to do anything that is asked of them, may not always be evident across different settings and with different people. Children with PDA, as with others on the spectrum, are often able to hold in their anxiety, difficulties and challenging behaviour with certain people and in certain situations, which is known as ['masking'](#). Some are even able to role-play the compliant child when they are with others, which is sometimes a coping strategy to remain below the radar of others and thus avoid demands.

But, this does not mean that the underpinning difficulties are not present at all times. The external presentation of a child, at school for example, is not always indicative of their internal state and ‘masking’ their difficulties is often at the expense of more challenging behaviour and/or more obvious signs of anxiety and depression at home. This is not due to a lack of parental care or woeful parenting in the home environment but is, instead, a sign that home is the only place where the child feels safe to truly be themselves.

The process of ‘masking’ can also be at the expense of their own emotional well-being and mental health. This can be especially so for older children who, with maturing years, develop improved social awareness of how their behaviour both affects and is interpreted by others. As a result, they may begin to internalize their difficulties both with others and at home, which may lead to the onset of mental health conditions such as depression, other anxiety disorders and eating disorders.

### **Imaginative Play**

Another feature that can often be atypical for children with the PDA profile is the presence of imaginative play, a lack of which is often seen as one of the features present in children with ASD. But, on closer inspection, this appearance of good imaginative play, may often be found to be steeped in repetition and/or copied from books, the television or other from other children. This play can also be rigid and inflexible, especially when they are playing with peers, where they will need to control and dominate the play.

### **Obsessions & Adherence to Routine**

Obsessive behaviour is seen in many children on the spectrum, but for children with the PDA profile their obsessions can often be social in nature from either a love or hate perspective, and can be focused on either real or fictional characters. Professor Elizabeth Newson et al also described that the avoidance of demands and the need to control had an ‘obsessive’ feel to it as did their love of role-play.

*The “pathological” nature of the demand avoidance means that it always has obsessional force; but role play is the second major obsession, which gives the impression of more socially oriented obsessions in PDA than in autism/Asperger’s syndrome. [Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders, 2003](#)*

Children with PDA may not respond well to routines that are imposed on them. But, as discussed by Dr Judith Gould (Dr Judith Gould is Director of the NAS Lorna Wing Centre for Autism) perhaps the need for routine for the child with PDA is expressed by their need to impose their own routine on others, by avoiding demands and controlling their own environment.

*The PDA group have been described as “hating routine and thriving on novelty” BUT are they imposing their routines by controlling the environment? Gould, National Autistic Society PDA Conference*

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## **2. The Quality and Nature of the Demand Avoidance**

The extreme nature of the demand avoidance and the strategies that an individual uses to avoid demands is also a key aspect in differentiating children with a typical profile of ASD,

who display some demand avoidance, compared to those with the PDA profile of ASD, who display extreme demand avoidance. As are the different strategies that are beneficial for these groups of children.

All children will sometimes avoid things that they don't want to do, or have a fear of doing, including those with other presentations of ASD. So, what differentiates the quality and the nature of avoidance that is seen in individuals with PDA from those with a more typical presentation of ASD?

**Firstly, lets take a look at how demand avoidance may present in an individual with a typical presentation of ASD.**

### **Demand avoidance in a typical presentation of ASD**

Individuals with a more typical presentation of ASD will often avoid demands or situations that are likely to include triggers which will increase their anxiety. Also, it can often be difficult to engage children with ASD in activities or events that they don't see the point of, or have a specific interest in. Some examples of the types of situations that may cause avoidance for individuals with a more typical presentation of ASD are listed below.

- Busy social occasions that will involve too much, anxiety provoking, social interaction e.g. school, birthday parties, family gatherings, play areas and parks
- Activities that are unplanned and unexpected which results in a variation to the child's usual routine. This may be something as simple as going home from school via a different route, in a different car, making a detour on the way home such as calling to the shop or doing something different at the weekend
- Activities or situations that will trigger sensory overload such as supermarkets, school, having their hair cut, people who wear a certain brand of perfume, activities that involve too much movement e.g. swings and roundabouts, engaging in messy play and wearing certain clothes to name but a few
- Activities or events that interrupt the pursuit of a special interest or that they don't enjoy or see the point of such as trying to engage them to go for a walk, do their homework, play outside or to spend time with family when they are engrossed on xbox and so on

### **How a child with a typical presentation is likely to avoid the demand**

The child may initially avoid the request, demand or an anxiety provoking situation by saying no, running off or withdrawing; pushing the child to comply may result in a meltdown. Meltdowns can be expressed in differing ways, the child may freeze, shut down, run off or display an outburst of challenging behaviour which may include verbal outbursts and, in some cases, physical aggression towards both property and other people.

### **Strategies to reduce the demand avoidance**

Often, this avoidance can be helped with the use of traditional ASD strategies which would focus on addressing any sensory issues, helping the child adjust to new situations, keeping to a routine, giving the child plenty of warning if a routine is going to deviate and by providing them with suitable support during these stressful periods.

**Now, we can have a look at how 'extreme' demand avoidance presents in an individual with the PDA profile.**

### **'Extreme' Demand Avoidance in a typical presentation of the PDA profile**

For individuals with PDA the avoidance will stem from situations such as those described above but also extends to all everyday demands, even when there is no apparent trigger for increased anxiety and stress associated with the demand. Because, for individuals with PDA, the trigger for avoidance extends to the demand, expectation or suggestion itself and doesn't necessarily always need to be accompanied with any additional triggers such as those that would cause avoidance for an individual with a more typical presentation.

This avoidance also extends to the person avoiding pleasant things that they would usually enjoy doing, such as engaging in a special interest, if to do so has become expected or suggested by others. In addition, individuals with PDA, will also struggle to comply with their own expectations and demands. An example of this could be that the person really wants to have a shower, but simply cannot cope with the self-imposed demand that this entails, and is therefore compelled to avoid their own demand against their own wishes.

**Anything and everything can trigger avoidance for the child who fits the PDA profile and avoidance is in no way limited to certain triggers or situations.**

### **How a child with a PDA profile is likely to avoid the demand**

As with other individuals with ASD the person with a profile of PDA may avoid demands by refusing, saying no, running off or withdrawing. However, unlike many individuals with a more typical presentation of ASD, the strategies that a person with PDA will often employ first and foremost, to avoid a demand, tend to be social in nature such as giving excuses, using distraction, drowning out the request with constant interruptions, disappearing into a fantasy world of role play or.

If these initial strategies are unsuccessful some children, but not all, may begin to use more challenging avoidance strategies such as shouting, swearing, socially shocking behaviour such as removing their clothes, hitting and damaging property to name but a few.

If the demand is pushed, as with others on the spectrum, this can quickly escalate into a meltdown. Meltdowns can be expressed in differing ways from freezing and completely shutting down to outbursts of physical violence towards others and property. These outbursts can last for hours.

The individual with PDA will often go to extreme measures to avoid, what appears to others, to be the simplest and most innocuous demand. e.g. watching a film that someone else has suggested, even if they like the film and have previously expressed a desire to watch it.

### **Strategies to support those with PDA**

Strategies that are often successful for reducing the demand avoidance seen in other individuals on the spectrum, such as an expected routine, rewards, timers, visual menus and clear agreed expectations do not tend to be successful for those with the PDA profile. This approach can often compound the demand even further and may often further exacerbate the situation.

For individuals with the PDA profile successful intervention isn't about trying to eliminate the demand avoidance but is, instead, about trying to work with the demand avoidance to

facilitate the child being able to access more opportunities.

This would involve offering limited choices, being flexible, phrasing demands in a non direct manner, providing opportunities and delivering strategies in stealth mode, and using negotiation that allows the child a sense of control and autonomy.

It is also important to address other areas of difficulty which could be exacerbating a child's inherent demand avoidance, such as sensory overload, emotional overload, communication difficulties, fear of uncertainty and so on.

But the strategies used, while often stemming from traditional ASD strategies, would need to be considerably adapted so that they are delivered in a non direct manner as described below.

E.G. a visual or written timetable may be helpful for a child with PDA to bring certainty about what to expect, but the child would likely need control over their own timetable to a large extent and be allowed to change and alter it depending on their levels of anxiety relating to demands at any given time.

E.G. Encouraging a child to wear headphones to reduce sensory overload when they are out and about may need to be delivered in a very non-direct manner e.g. discussing with someone else, in ear shot of the child but not to the child, how headphones can keep children calm when they are in noisy places because it cuts out a lot of stressful background noise. Then skilfully leave a few sets of headphones out and about around the house, in the hope that the child will pick them up and begin wearing them of their own volition.

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### **3. Key Features of the PDA Profile**

In addition to the presence of ASD features and the type of extreme demand avoidance that is detailed above, children with the PDA profile will also display many of the key features of the PDA profile.

A key point to remember is that some children with ASD could display one or more of the key features of PDA. But it is when many of the key features of PDA occur together, in conjunction with the other difficulties shared by those on the spectrum, that it is helpful to have a diagnosis of ASD with a profile of PDA because of the implications that this has for successful intervention and management.

1. Resists and avoids the ordinary demands of life
2. Uses social strategies as part of avoidance
3. Appears sociable but lacks understanding
4. Experiences excessive mood swings and impulsivity
5. Appears comfortable in role play and pretence
6. Displays obsessive behaviour that is often social in nature

A more detailed explanation of these key features and how they present can be found by following the link provided [The National Autistic Society – What is PDA?](#)

## Further resources

The PDA Society provide a full list of 'audience targeted' resources on their website [PDA Society Resources](#)

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#### About janesherwin

I am the parent of a child diagnosed with Pathological Demand Avoidance Syndrome. My hopes and aims are to raise awareness of this complex Autism Spectrum Condition presentation.

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## 4 Responses to *Does My Child Present with PDA Profile of ASD?*



**dragonriko** says:

July 27, 2017 at 2:52 pm

Thanks, this is brilliant. Have shared it around

Like

[Reply](#)



**janesherwin** says:

July 28, 2017 at 11:40 pm

Thanks Riko, I'm pleased that you like it and thanks for sharing

Liked by [1 person](#)

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**notesonpda** says:

July 27, 2017 at 4:34 pm

This is excellent – thank you for putting all of this together in one place so clearly!

Like

[Reply](#)



**janesherwin** says:

July 28, 2017 at 10:03 am

Thank you and you're very welcome. I'm pleased that it reads clearly, it took a long time to think of how to try to unpick everything and then how to lay it out in a format that would make sense. So, it is great to hear that it seems to meet these points

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