

Pathological Demand Avoidance?

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 better social understanding and communication skills than others on the spectrum and 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. There may be neurological involvement in some cases, with a higher than usual incidence of clumsiness and other soft neurological signs.

Other children and young people on the autism spectrum can display one or more of the features of PDA. When many occur together it is helpful to use the PDA diagnosis, as the strategies and interventions that help a person with PDA differ to those that benefit others on the autism spectrum.

People with PDA can be controlling and dominating, especially when they feel

anxious. However, they can be enigmatic and charming when they feel secure and in control. Many parents describe their child with PDA as a 'Jekyll and Hyde' character. It is important to acknowledge that these children have a hidden disability. Many parents of children with PDA feel that they have been wrongly accused of poor parenting through lack of understanding about the condition. These parents will need a lot of support, as their children can often present severe behavioural challenges.

People with PDA are likely to need a lot of support into their adult life. Limited evidence so far suggests that the earlier the diagnosis and the better support that they have, the more able and independent they are likely to become.

Getting a diagnosis

A diagnosis is the formal identification of PDA, usually by a professional such as a paediatrician, psychologist or psychiatrist. Recognition of PDA as a condition is fairly recent, and the apparent social abilities of many children with PDA mask their problems. Many children are not diagnosed until they are older and may already have a diagnosis of autism or Asperger syndrome. Sometimes parents may feel that something about this diagnosis doesn't quite fit. It is usually the surface sociability and the often vivid imaginations of children with PDA which confuse professionals.

Having a diagnosis of PDA is helpful for a number of reasons as it:

- helps people with PDA and their families to understand why they experience certain difficulties and what they can do about them
- allows people to access services, support and appropriate advice about management strategies
- avoids other incorrect diagnoses and assumptions
- informs local authorities and schools about the importance of providing support and using appropriate PDA strategies and interventions. This helps to avoid school exclusion.

To begin the diagnosis process, ask your GP for a referral to a local paediatrician or team who specialise in autism spectrum disorders. The recognition of PDA and ability to make a differential diagnosis may vary regionally, but it should still be possible for whoever you see to give you a detailed profile of your child's strengths and needs.

The PDA society has produced "Awareness Matters", a reference booklet for clinicians that may also be useful to parents and education professionals.

The characteristics of PDA

The main characteristic of PDA is a high level of anxiety when demands are placed on that person. Demand avoidance can be seen in the development of many children, including others on the autism spectrum. It is the extent and extreme nature of this avoidance that causes such difficulties, which is why it has been described as 'pathological'.

Resists and avoids the ordinary demands of life

This is the feature of behaviour that gives the name to the syndrome. Children can seem under an extraordinary degree of pressure from everyday expectations and they may attempt to avoid these to a huge extent. Demands might include a suggestion that it's time to get up, go out of the house or join a family activity. At times **any** suggestion made by another person can be perceived as a demand.

For some, avoidance may seem their greatest social and cognitive skill and the strategies they use are essentially socially manipulative. These can include:

- distracting the adult
- acknowledging the demand but excusing self
- procrastination and negotiation
- physically incapacitating self
- withdrawing into fantasy
- physical outbursts or attacks.

Underpinning this avoidance is an anxiety about conforming to social demands and of not being in control of the situation.

Of course, children with autism may also react to social demands by becoming avoidant but they tend to do this in ways that aren't very social in nature (e.g. ignoring, withdrawing or walking away). A key feature of PDA is that the child has sufficient social understanding to use a level of social manipulation in their attempts and will often adapt strategies to the person making the demand.

Parents very often use the term 'manipulative' to describe this aspect of their child's behaviour and will comment on how it seems to be their greatest skill, often saying "if only they would put half the effort in to doing what it was I wanted as they do to getting out of it."

Those with PDA may also use straightforward refusal or outbursts of explosive behaviour, including aggression. This is a form of panic on their part and is usually displayed when other strategies haven't worked or when their anxiety is too high that they will 'explode' or have a 'meltdown'. This can take the form of shouting, screaming, throwing things and physically lashing out, often in a very sudden and dramatic way. Not all individuals with PDA have explosive outbursts, but it seems to affect a significant number.

Appearing sociable, but lacking depth in understanding

Children with PDA tend to:

- appear social at first and be 'people-orientated'
- have learnt many social niceties and may decline a request politely
- seem well tuned in to what might prove effective as a strategy with a particular person
- be unsubtle and lack depth. They can be misleading, overpowering and may over react to seemingly trivial events
- have difficulty seeing boundaries, accepting social obligation and taking responsibility for their actions.

A feature of this poor judgement is an ambiguity in their mood and responses (e.g. hugging becomes pinching or a child may embrace their parent while saying something like "I hate you"). This demonstrates both their own confusion

and the fact that their behaviour can be confusing to others.

Edward's parents talked about how he treats everyone the same. "He's got no sense of authority and doesn't recognise 'a pecking order'. He generally relates well to adults and responds better if you adopt an adult style of speech to him. He talks to other children as though he was an adult or in a teacher role and, for example, will try to stop children going out to play if it's raining. He treats his niece in the same way as his parents do, as though he was just another adult."

Individuals with PDA often fail to understand the unwritten social boundaries that exist between adults and children. They can become overfamiliar or come across as bossy. They also seem to lack a sense of pride or embarrassment and can behave in uninhibited ways.

Excessive mood swings and impulsivity

People with PDA switch from one mood to another very suddenly in a way that can be described as "like switching a light on and off". The emotions shown may seem dramatic and over the top or, according to some parents, like an act.

Difficulty with regulating emotions is common in all children on the autism spectrum, but early studies found it especially prevalent in PDA. Mood swings and impulsivity, were also shown to persist beyond childhood in the majority of those with PDA. This switching of mood often seems to be driven by the child's need to control and they can:

- switch moods rapidly, often for no obvious reason
- switch moods as a response to a perceived pressure
- change mood in an instant if they suspect that someone else is exerting control.

Rapid and often unexpected changes of moods, together with their overall variability of behaviour, can make children with PDA very unpredictable.

Role play and pretend

Children with PDA are often highly interested in role play and pretend. This was recognised early on as being different from other children on the autism spectrum. Children with PDA often mimic and take on the roles of others, extending and taking on their style, not simply repeating and re-enacting what they may have heard or seen in a repetitive or echoed way. About a third of children in early studies were reported to confuse reality and pretence at times.

Individuals with PDA, especially children, will often incorporate role play or pretend in the strategies that they use to avoid demands or exercise control. When they become involved in play scenarios with other people, they will nearly always try to direct and this can cause real conflict, especially with other children.

Language delay

The large majority of children with PDA are delayed in some aspect of their early speech and language development, although this may be dependent on their intellectual ability.

This initial delay seems to be part of their overall passivity and there is often a sudden degree of catch-up.

Individuals with PDA have more fluent use of eye contact (other than when avoiding demands) and conversational timing than others on the autism spectrum. Generally, they tend to have less difficulty understanding non-verbal communication. However, some do have difficulties such as taking things literally and understanding sarcasm and teasing.

While the majority of people with PDA become fluent in using expressive language, some have a problem with their understanding. They can have difficulty with processing what they hear and need additional time to do this. This can lead to misunderstandings and disruption to the communication process which can contribute to their behaviour.

Obsessive behaviour, often focused on people

Strong fascinations and special interests pursued to an 'obsessive' degree are very characteristic of children across the spectrum. Due to that this characteristic does not distinguish a child with PDA from others on the autism spectrum. However, Elizabeth Newson noted that demand avoidant behaviour itself usually has an 'obsessive feel'.

Children with PDA may have a strong fascination with pretend characters and scenarios. The subjects of fixations for people with PDA can also revolve around specific individuals they interact with. This can result in blame, victimisation and harassment that cause problems with peer relationships.

Sensory differences

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.

Severe behavioural difficulties

A large proportion of people with PDA can have real problems controlling their temper. As children, this can take the form of prolonged meltdowns as well as less dramatic avoidance strategies like distraction, giving excuses etc. It is essential to see this as extreme anxiety or 'panic attacks' and to treat them as such. Try using reassurance, calming strategies and de-escalation techniques.

Children with PDA can appear very anxious at home but remain relatively passive at school. This is a learnt coping strategy that can make parents feel very isolated and inadequate. In other cases, outbursts are far worse at school, where demands may be much greater and this can lead to multiple exclusions at an early age. For some children, this anxiety can develop to such an extent that they become school refusers.

Other conditions and overlaps

PDA is often diagnosed alongside other conditions, such as ADHD, dyslexia, and dyspraxia. This may be a result of overlapping conditions but can also be due to confusion over the diagnosis. Before being diagnosed with PDA, some people will have already been diagnosed with autism, ASD or atypical autism.

PDA can also be present alongside more generalised learning difficulties and, at times, the apparent verbal fluency of people with PDA can mask genuine difficulties in understanding.

Guidelines for parents

Many parents find that their usual approaches (including tried and tested autism strategies) for coping with and supporting their child with PDA are not effective. This is because people with PDA need a less directive and more flexible approach than others on the autism spectrum. Underpinning this approach is the understanding that a person with PDA does not make a deliberate choice to not comply and they cannot overcome their need to be in control. However, with the right support, they may begin to make adjustments as trust and confidence builds.

Education approaches

There is currently no cure for a person with PDA but our knowledge about appropriate interventions and educational approaches is growing.

One of the most important reasons for distinguishing PDA from other conditions is to ensure that the child receives the correct educational approach. Best practice differs fundamentally between children with PDA and children with autism. This has been acknowledged with the publication of specific guidelines for children with PDA, point 5.2 of the National Autism Standards published by the Autism Education Trust.

The use of structured teaching methods, which are so successful for people with autism and Asperger syndrome, are usually much less helpful for people with PDA and need considerable adaptation.

People with PDA do not respond to structure and routine and prefer to be taught in a more indirect way using a style that allows them to feel in control.

What causes PDA and who are affected?

The exact cause of PDA is still being investigated. However, as with autism and Asperger syndrome, research suggests that a combination of factors, genetic and environmental, may account for changes in brain development. Unlike autism and Asperger syndrome PDA seems to affect boys and girls equally. There are no prevalence rates for PDA as yet. It seems likely that the genetic factors are similar to those in autism and that about six percent of children with PDA are known to have a sibling with an autism spectrum disorder. As more diagnoses of PDA are made, prevalence figures will become more apparent. PDA affects people from all backgrounds and nationalities.

History and recent research

Pathological Demand Avoidance (PDA) was a term first used by Professor Elizabeth Newson in the 1980s, to describe the profile of a group of children she had seen for assessment at the Child Development Research Unit in Nottingham. Her initial writings were informally published as a part of conference proceedings. The first journal article appeared in 2003. These are available through the Elizabeth Newson Centre publication list.

Recent research has seen the development of a questionnaire called the Extreme Demand Avoidance Questionnaire (EDA-Q) designed to identify individuals with possible PDA for research purposes. Some researchers or clinicians have started to use the term 'extreme' alongside that of 'pathological'. This means that you might come across descriptions such as extreme/pathological demand avoidance.

Many parents have found the EDA-Q helpful when considering if their child's development might fit this profile.

Recommended reading

Educational and Handling Guidelines for Children with PDA and Simple Strategies for Supporting Children with Pathological Demand Avoidance at School by Emma Gore Langton and Zoe Syson are available from the PDA society.

Understanding Pathological Demand Avoidance Syndrome in children

A guide for parents, teachers and other professionals. By Phil Christie, Margaret Duncan, Zara Healy and Ruth Fidler.

Can I tell you about Pathological Demand Avoidance Syndrome?

A guide for friends, family and professionals. By Ruth Fidler and Phil Christie, illustrated by Jonathon Powell

Web resources

www.autism.org.uk/pda

[NAS Autism Helpline](#)

[The PDA Society](#)