

Pathological demand avoidance (PDA).

What is pathological demand avoidance (PDA)?

Pathological demand avoidance (PDA) is increasingly, but not universally, accepted as a behaviour profile that is seen in some individuals on the autism spectrum.

People with a demand avoidant profile share difficulties with others on the autism spectrum in social communication, social interaction and restricted and repetitive patterns of behaviours, activities or interests.

However, those who present with this particular diagnostic profile are driven to avoid everyday demands and expectations to an extreme extent. This demand avoidant behaviour is rooted in an anxiety-based need to be in control.

While the demand avoidant profile has been found to be relatively uncommon, it's important to recognise and understand the distinct behaviour profile as it has implications for the way a person is best supported.

Features of a demand avoidant profile.

People with a demand avoidant profile can appear to have better social understanding and communication skills than others on the autism spectrum, and are often able to use this to their advantage. However, they might not really have as good an understanding of social matters as it seems.

The distinctive features of a demand avoidant profile include:

- resists and avoids the ordinary demands of life
- uses social strategies as part of avoidance, e.g. distracting, giving excuses
- appears sociable, but lacks understanding
- experiences excessive mood swings and impulsivity
- appears comfortable in role play and pretence
- displays obsessive behaviour that is often focused on other people.

People with this profile can appear controlling and dominating, especially when they feel anxious. However, they can also be enigmatic and charming when they feel secure and in control. It's important to acknowledge that these people have a hidden disability.

People with a demand avoidant profile are likely to need a lot of support. The earlier the recognition of PDA, the sooner appropriate support can be put in place.

PDA in the early years

According to the Elizabeth Newson Centre, many people with a PDA behaviour profile had a passive early history. This means that as infants, they:

- didn't reach
- dropped toys
- 'just watched'
- were delayed reaching milestones.

As an infant grows, and more is expected of them, they can begin to strongly object to and resist normal demands. A few actively resist from the start – everything is on their own terms.

Many parents of children with a demand avoidant profile feel that they have been wrongly accused of poor parenting through a lack of understanding. These parents need a lot of support, as their children can present with severe behavioural challenges.

The characteristics of PDA

The main characteristic of a demand avoidant profile is a high level of anxiety when demands are placed on that person. Demand avoidance can be seen in the development of children, including those on the autism spectrum. It's the extent and extreme nature of this avoidance, together with displays of socially shocking behaviour that leads to it being described as 'pathological'.

Resists and avoids the ordinary demands of life

People with PDA can appear to be very stressed by even simple everyday expectations and they may attempt to avoid these to a remarkable extent.

Demands might include a suggestion that it's time to get up, go out of the house or join an activity. At times any suggestion made by another person can be perceived as a demand.

This may even be the case when the person seems to want to do what has been suggested

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

- distracting the person making the demand
- acknowledging the demand but excusing themselves
- procrastination and negotiation
- physically incapacitating themselves
- 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.

People with other autism profiles may also react to social demands by becoming avoidant but tend to do this in ways that aren't very social in nature e.g. ignoring, withdrawing or walking away.

Someone with a demand avoidant profile may seem to have enough social understanding to adapt their 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 probably a form of panic on their part and is usually displayed when other strategies haven't worked or when their anxiety is so high that they 'explode' or have a 'meltdown'. This can be suddenly shouting, screaming, throwing things and physically lashing out.

Appear sociable, but lack depth in understanding

People with a demand avoidant profile tend to:

- appear social at first and be 'people-orientated'
- have learnt many social niceties and may decline a request or suggestion 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 overreact to seemingly trivial events
- have difficulty seeing boundaries, accepting social obligation and taking responsibility for their actions
- display confusing behaviour and contradictory moods, eg hugging becomes pinching or a child may embrace their parent while saying something like "I hate you"
- as children, lack a sense of pride or embarrassment, and behave in uninhibited ways
- as children, fail to understand the unwritten social boundaries that exist between adults and children and can become overfamiliar or bossy.

Excessive mood swings and impulsivity

Difficulty with regulating emotions is common in autistic people, but early studies found it especially prevalent in people with a demand avoidant profile. They may switch from one mood to another very suddenly in a way that can be described as "like switching a light on and off".

To other people, the emotions can seem very dramatic and over the top, like an act, and there's sometimes no obvious reason.

But this switching of mood can be in response to perceived pressure or a demand, and is driven by the need to control.

It can make children with a demand avoidant profile very unpredictable. For most, this difficulty continues into adulthood.

Comfortable in role play and pretend, sometimes to an extreme extent

People with a demand avoidant profile, especially children, are often highly interested in role play and pretend, sometimes to an extreme extent. They will often use role play or pretend as part of a strategy 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.

This was recognised early on as being different from many other children on the autism spectrum. Children with a demand avoidant profile 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. This is also the case for many people with other autism behaviour profiles.

Language delay, often with good degree of catch-up

The large majority of children with a demand avoidant profile are delayed in some aspect of their early speech and language development, although this may be dependent on their intellectual ability, and there is often a sudden degree of catch-up.

People with a demand avoidant profile have a more socially accepted 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 a demand avoidant profile become fluent in using expressive language, some have a problem with their understanding. They can have difficulty with processing what they hear and they need additional time to do this.

These difficulties may lead to misunderstanding 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 people with all autism profiles. However, Elizabeth Newson noted that the demand avoidant behaviour itself usually has an 'obsessive feel'.

People with a demand avoidant profile may have a strong fascination with pretend characters and scenarios or real people they interact with. This can result in blame, victimisation and harassment that cause problems with peer relationships.

Sensory differences

Just as in other autism profiles, people with this profile 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 a demand avoidant profile can have real problems controlling and regulating their emotions, particularly anger. As children, this can take the form of prolonged meltdowns as well as less dramatic avoidance strategies like distraction and giving excuses. 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.

Similar to others on the autism spectrum, the behaviour of a person with a demand avoidant profile can vary between settings. For example, a child can appear very anxious at home, but calm at school. This is a learned coping strategy, and a lack of understanding of the real reasons for these differences 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.

Getting an assessment

As PDA is considered to be a behaviour profile within the autism spectrum, it is usually identified following a diagnostic assessment for autism. This is usually by a multi-disciplinary team made up of a combination of professionals including: paediatricians, clinical and educational psychologists, psychiatrists, speech and language therapists and occupational therapists.

Recognition of demand avoidance as a behaviour profile within the autism spectrum is fairly recent, and the apparent social abilities of many children with this profile mask their problems. Many children are not identified until they are older and may already have been diagnosed with a different autism profile. Sometimes parents may feel that this different profile doesn't quite fit. It's usually the surface sociability and the often vivid imaginations of children with a demand avoidant profile that can confuse professionals making the diagnosis.

Other autistic children and adults can display one or more of the behavioural features of PDA. When many occur together it is helpful to have a diagnosis of demand avoidant profile because 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 strategies
- avoids incorrect assumptions and diagnoses, such as Personality Disorder, Oppositional Defiance Disorder, ADHD, dyslexia or dyspraxia (although a person might have these as well)
- informs local authorities and schools about the importance of providing support and using appropriate strategies and interventions, which differ to those that benefit others on the autism spectrum. This helps to avoid school exclusion.

To begin the assessment process, ask your GP for a referral to a local paediatrician (if for your child) or team who specialise in autism. If your child is in school, talk more with their teacher and SENCo to find out how they can help.

The recognition of PDA and the skills in local teams to make an assessment may vary regionally. However, it should still be possible for whoever you see to give you a detailed profile of your child's strengths and needs. PDA is not currently recognised as a discrete diagnosis within national and international standards.

The PDA Society also have information about the diagnostic pathway for children and adults.

<https://www.pdasociety.org.uk/>

Guidelines for parents

A large number of parents find that tried and tested strategies used with children who have other autism profiles are not effective for their child with a demand avoidant profile. This is because people with this profile 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 can't overcome their need to be in control. However, with the right support, they may begin to make a series of achievements as trust and confidence builds.

The PDA society has very useful information for families on their website.

<https://www.pdasociety.org.uk/>

Education – intervention and approaches

Our knowledge about appropriate interventions and educational approaches is growing.

One of the most important reasons for distinguishing this demand avoidant behaviour profile from other conditions and autism profiles is to ensure that the child is supported by the right educational approach. Best practice differs for children with this profile and this has been acknowledged with the publication of specific guidelines for children with PDA as part of England's National Autism Standards.

The use of structured teaching methods, which can be useful for people with other autistic profiles if individual needs have been considered, are often much less helpful for people with a demand avoidant profile and need considerable adaptation. People with this profile don't usually respond to structure and routine. An indirect style of negotiation is more likely to lead to them feeling the control over their learning that they need.

What causes PDA and who is affected?

PDA affects people from all backgrounds and nationalities. The cause of this, along with other autism profiles, is still being investigated. You can read more about the causes of autism.

Demand avoidant behaviour profiles are seen in people of all genders, and this seems to be in equal proportions. This means that women are as likely to have this profile as men.

There are no prevalence figures as yet, but these will become more apparent as more people with a PDA profile are identified.

Recommended reading

[Understanding Pathological Demand Avoidance Syndrome in children](#)

[Can I tell you about Pathological Demand Avoidance Syndrome?](#)

Web resources

[What is Pathological Demand Avoidance? An adult's perspective](#)

[PDA and mental health](#)

[Educational and Handling Guidelines for Children with PDA](#)

Information taken from National Autistic Society Website, www.autism.org.uk

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