# PDA (Pathological demand avoidance syndrome)

**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.**
PDA is increasingly recognised as part of the autism spectrum. Here, we explain the characteristics of PDA and what can be done to support someone who has the condition.

## What is PDA?

PDA, first described by Elizabeth Newson during the 1980s as a pervasive developmental disorder distinct from autism, is increasingly becoming recognised as part of the autism spectrum. It is a lifelong disability and, as with autism and Asperger syndrome, people with PDA will require different amounts of support depending on how their condition affects them.

The central difficulty for people with PDA is their avoidance of the everyday demands made by other people, due to their high anxiety levels when they feel that they are not in control. Hence the name of the syndrome: pathological demand avoidance.
People with PDA tend to have much better social communication and interaction skills than other people on the spectrum, and are consequently able to use this ability to their advantage. They still have real difficulties in these areas though, usually because they need to control the interaction. They often have highly developed social mimicry and role play, sometimes becoming different characters or personas.

**The main features of PDA are:**

- obsessively resisting ordinary demands
- appearing sociable on the surface but lacking depth in their understanding (often recognised by parents early on)
- excessive mood swings, often switching suddenly
- comfortable (sometimes to an extreme extent) in role play and pretending
- language delay, seemingly as a result of passivity, but often with a good degree of 'catch-up'
- obsessive behaviour, often focused on people rather than things.

Often in cases of PDA there will have been a passive early history, but this is not always the case. It is believed that there may be neurological involvement in some cases, with a higher than usual incidence of clumsiness and other soft neurological signs.

The main features of PDA are described in more detail below. Other children on the autism spectrum can display one or more of these features but when many occur together it is helpful to use the diagnosis of PDA because things that help people with autism or Asperger syndrome do not always help those with PDA.

People with PDA can be controlling and dominating, especially when they feel anxious and are not in charge. They can however be enigmatic and charming when they feel secure and in control. Many parents describe their PDA child as a 'Jekyll and Hyde'. It is important to recognise that these children have a hidden disability and often appear 'normal' to others. 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 themselves, 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.

# What are the characteristics of PDA?

The main characteristic of PDA is high anxiety when demands are made on the person. Demand avoidance can be seen in any child with an autism spectrum disorder but when the avoidance reaches pathological levels, major difficulties arise.

**Resisting demands obsessively**

This is the overriding criterion for diagnosis. People with PDA become experts at avoiding demands - they seem to feel an extraordinary amount of pressure from ordinary everyday expectations. It is often not the activity itself that is a pressure but the fact that another person is expecting them to do it. The person's threshold or tolerance can vary from day to day, or moment to moment. It is important to realise that the more anxious a person with PDA is, the less they will be able to tolerate demands. As a child, their avoidance of those making demands on them knows no boundaries and usually includes a level of social manipulation. Strategies range from simple refusal, distraction, giving excuses, delaying, arguing, suggesting alternatives and withdrawing into fantasy. They may also resist by becoming physically incapacitated (often accompanied by an explanation such as "my legs don't work" or "my hands are made of lava"). If pushed to comply, they may become verbally or physically aggressive, with severe behavioural outbursts, best described as a 'panic attack'.

One paediatrician, describing a child at five, wrote:

> He has a wide variety of strategies to avoid obeying direct demands. He acts as if he has not heard, carrying on with what he's doing with a blank expression on his face. He distracts by starting to talk about something else and he will go on until his mother has forgotten what she wanted him to do. He makes excuses such as 'I've just got to' He says 'I can't' in a plaintive voice or falls to the floor and starts rolling around like a baby.

**Appearing sociable but with difficulties recognised by parents**

People with PDA are often very sociable and can display degrees of empathy previously not thought to be consistent with autism. Sometimes it seems that they are able to understand other people at an intellectual level but not at an emotional one. However, despite their use of social niceties, their social interaction is very often flawed by their inability to see the bigger picture, their lack of boundaries and their desire to be in control of the situation. They often understand rules but don’t feel they apply to themselves.

As children, this can lead to playground peer group difficulties. One parent described how "to other children he will happily act as if he was their mother - 'have you washed your hands' or 'don't put your elbows on the table' - but he doesn’t have a sense of needing to follow the same rules."

As adults, further education and employment difficulties may be apparent, but some adults with PDA enjoy success in both.

**Excessive mood swings, often switching suddenly**

People with PDA may switch from one state to another very quickly (eg from contented to aggressive), driven by the need to be in charge. This may be in response to perceived expectations. One parent described her 17-year-old son with PDA as "always imagining the worst case scenario" and this often being a trigger for outbursts.

**Comfortable (sometimes to an extreme extent) in role playing and pretending**

When they are younger, children with PDA often engage in a level of pretend play that would be unexpected from children with autism or Asperger syndrome. People with PDA are very good at taking on the roles and styles of others. The classic example is children who behave as if they were the teachers to other children. One mother described how her daughter would cope with a class of 30 or more imaginary children, commenting on them and talking to them; "She'll say, 'Oh, Callum's not here today, he's sick; Jason, you're not listening', then she will arrange pieces of paper for the class and move them from one room to another as a line of children." In extreme cases, children can become so engrossed in this role playing that they lose touch with reality.

**Language delay, seemingly as a result of passivity**

Although people with PDA may have some language delays at an early age, there is often a striking and sudden degree of catch-up. Certain elements of communication are not as disordered as in autism or Asperger syndrome, with more fluent use of eye contact (other than when avoiding demands) and better conversational timing. Some language difficulties remain, such as taking things literally and misunderstanding sarcasm and teasing. As an extreme form of avoidance, some children become selectively mute in many situations, yet their parents know they can speak when they want to.

**Obsessive behaviour**

The sort of avoidance that has been described is often linked to an obsession with a particular person (or less frequently, an object). Obsessions will vary from person to person but are often social in nature. Sometimes, obsessions with particular people can become problematic and overbearing for those who are on the receiving end.

# Other related characteristics

**Sensory sensitivities**

Just as in autism and Asperger syndrome, people with PDA can often experience over- or under-sensitivity in any of their senses: sight, smell, taste, touch or hearing.

**Other conditions and areas of overlap**

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, PDD-NOS 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.

**Severe behavioural difficulties**

A large proportion of, but not all, people with PDA can have real problems controlling their temper. As children, this can take the form of prolonged tantrums and violent outbursts, as well as less dramatic avoidance strategies like distraction, giving excuses etc. It is essential to see these outbursts as extreme anxiety or 'panic attacks' and to treat them as such, with reassurance, calming strategies and de-escalation techniques.

Sometimes a child with PDA can appear very anxious at home but remain relatively passive at school (a learnt coping strategy). In situations like this, parents are likely to 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.

# Who is affected by PDA?

Unlike autism and Asperger syndrome, both of which seem to affect more boys than girls, PDA affects 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 6% 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.

# What causes PDA?

The exact cause of PDA is still being investigated. We do know that, as in autism and Asperger syndrome, it is linked to a hard-wiring problem in the brain. It is likely to be caused by a combination of factors, genetic and environmental, which may account for changes in brain development.

It is important to remember that PDA is not caused by a person's upbringing or their social circumstances and it is not the fault of the parents or the individual with the condition.

# Is there a cure?

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. 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. One teacher, describing a pupil in a mainstream class, wrote:

> We have found that the more routine there is, the worse he is - you need to catch him unawares. We have tried using behavioural approaches with him but they have not worked. He doesn't seem to understand rewards - he will snatch the reward and then not do the task. He has his set agenda and is always in control of the situation.

People with PDA tend to respond much better to a more indirect and negotiative style that allows them to feel in control.

# What is 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 may mask their problems. As a result, many children are not diagnosed until they are older. They may already have had a suggested diagnosis of autism or Asperger syndrome but parents may feel that something about that diagnosis didn't quite fit. It is usually the surface sociability and the often vivid imaginations of children with PDA which confuse professionals regarding the autism spectrum diagnosis.

**Having a diagnosis of PDA is helpful for a number of reasons:**

- It helps people with PDA (and their families) to understand why they experience certain difficulties and what they can do about them.
  It allows people to access services, support and appropriate advice about management strategies.
- It avoids other incorrect diagnoses (eg attachment anxiety disorder, ODD, emotional and behavioural problems or having a wilful and naughty child).
- It warns local authorities that this diagnosis can sometimes result a high exclusion rate unless sufficient support is provided.

One parent described how:

> It was a huge consolation to find a set of characteristics and criteria that seemed to have been made for my child here was a tailor-made paper on my child.

To get a diagnosis, a GP referral to a local paediatrician who specialises in autism spectrum disorders may be sufficient. If local paediatricians are not yet familiar with diagnosing PDA, advice could be offered by the Elizabeth Newson Centre, part of Sutherland House Children's Services (www.norsaca.org.uk).