

## **PE1625/C**

National Autistic Society Scotland Letter of 15 February 2017

### **What is Pathological Demand Avoidance?**

Pathological demand avoidance (PDA) is increasingly, but not universally, accepted as a behaviour profile that is seen in some individuals on the autism spectrum. The National Autistic Society Scotland accepts the condition as an autism behaviour profile.

People with a PDA behaviour 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.

### **What causes PDA and who is affected?**

The cause of PDA, along with other autism profiles, is still being investigated.

The PDA behaviour profile is 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.

PDA affects people from all backgrounds and nationalities.

### **When was PDA first identified, and by who?**

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 part of conference proceedings, until the first journal article appeared in the Archives of Diseases in Childhood in 2003.

Recent research has seen the development of 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.

### **What are the characteristics of PDA?**

The main characteristic of PDA is a high level of anxiety when demands are placed on a 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'.

People with PDA 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 PDA profile include:

- resisting and avoiding the ordinary demands of life
- using social strategies as part of avoidance, e.g. distracting, giving excuses
- appearing sociable, but lacking understanding
- experiencing excessive mood swings and impulsivity
- appearing comfortable in role play and pretence
- displaying obsessive behaviour that is often focused on other people.

Those with PDA 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.

### **What does PDA look like in children?**

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 a child 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 PDA 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.

### **How is PDA diagnosed?**

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.

The recognition of PDA and the skills in local teams to make an assessment may vary regionally. PDA is not currently recognised as a discrete diagnosis within national and international standards.

### **Why is diagnosis important?**

Diagnosis can:

- help people with PDA and their families to understand why they experience certain difficulties and what they can do about them
- allow people to access services, support and appropriate advice about strategies
- avoid incorrect assumptions and diagnoses, such as Personality Disorder, Oppositional Defiance Disorder, ADHD, dyslexia or dyspraxia (although a person might have these as well)
- inform local authorities and schools about the importance of providing support and using appropriate PDA strategies and interventions, which differ to those that benefit others on the autism spectrum. This helps to avoid school exclusion.

### **Why can diagnosis be difficult?**

Recognition of PDA as a behaviour profile within the autism spectrum is fairly recent, and the apparent social abilities of many children with PDA 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 the PDA profile which confuse professionals regarding the diagnosis.

### **How can PDA affect a child's education?**

One of the most important reasons for distinguishing this PDA 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 PDA profile and need considerable adaptation. People with a PDA profile do not 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.

**Does The National Autistic Society Scotland believe that Scottish Government should promote a wider awareness and acceptance of PDA syndrome among health, education and social care and social work practitioners?**

Yes. We believe that greater awareness of PDA is important so that clinicians can provide a more accurate profile of a person's strengths and needs following a diagnostic assessment, in turn leading to more appropriate support.

**Does The National Autistic Society Scotland believe that Scottish Government should institute and facilitate training in the diagnosis of the condition, to promote the development of therapeutic programmes for those with the syndrome and to provide support for their families and carers?**

Yes. In a survey of autistic people and family members in Scotland, carried out by our charity, 50 per cent of respondents said they thought professional understanding of autism was poor or very poor. Anecdotally, we hear from parents that understanding among professionals of how someone with a PDA behaviour profile may present and the different strategies and type of support they might need is even lower.

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