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Avoiding the subject

Pathological demand avoidance syndrome has long resided at the forgotten end of the autistic spectrum, but things may be starting to change. Margaret Duncan looks at what PDA is and why it matters

There is increasing awareness and recognition of a sub group of autism spectrum disorders (ASDs) called pathological demand avoidance syndrome (PDA). This is a neurodevelopment condition, characterised by an anxiety-led need to control which manifests itself in the avoidance of everyday demands (to a pathological degree). Over the last few years, the National Autistic Society (NAS) has held four conferences across the UK on the subject of PDA, and another one is due in Cardiff this year. These have been extremely well attended, even in this austere climate, because parents, teachers and other professionals are thirsty for knowledge of this emerging

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condition. They recognise the features all too well and, more importantly, they are realising that the guidelines for managing these children work more effectively than guidelines for more typical ASDs.

Children with PDA experience high rates of school avoidance, exclusions, and mental health problems, including very low self-esteem, and their families

can experience a huge amount of stress, often despite input from many professionals, including multi-agency support teams (MAST), child and adolescent mental health teams (CAMHS), social services (SS) and sometimes even the local constabulary.

A lack of understanding

Unfortunately, diagnosis of PDA is not straightforward. It depends on which area you are in, which professional you see and whether or not the area decides to “recognise” the condition or even acknowledge its existence. This is due to its status of not being in the Diagnostic and Statistical Manual of Mental Disorders (DSM) in America

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Anxiety and a need to control can underpin the avoidance of everyday demands.

and International Classification of Disease (ICD). To gain recognition in these manuals, the condition has to fulfil certain criteria usually pertaining to research. Unfortunately, there hasn't, until recently, been a great deal of research on PDA other than the original studies by Professor Elizabeth Newson and subsequent papers by Phil Christie.

Schools and parents, however, are experiencing PDA first hand. They recognise the features of PDA in their children and are crying out for help with the condition. The good news is that research is now being done. Indeed, the most recent research conducted by Liz O'Nions, comparing anxiety scores in children with oppositional defiant disorder (ODD), PDA or conduct disorder (CD) is very encouraging, showing a distinctly much higher anxiety level in those with PDA. She has developed a parent/teacher questionnaire that can be used as a tool to measure severity of demand avoidance. This research has been published recently in the Journal of Child Psychology and Psychiatry.

Diagnostic criteria for PDA

The diagnostic criteria for PDA are essentially:

1. passive early history (although some are actively resistant from the start)
2. excessively avoiding demands of everyday life to a pathological degree
3. some form of language developmental delay but usually with a good degree of catch up
4. obsessions
5. surface sociability
6. lability of mood or impulsiveness
7. comfortable in role play and pretending (sometimes to extreme levels)
8. neurological involvement.

They frequently sabotage their friendships by their persistent need to be in control

What is PDA?

The diagnostic criteria for PDA can be seen in the box (below left), but the overriding major feature is the child's ongoing resistance to the everyday demands of ordinary life, even to his or her own detriment. This appears to be linked to an anxiety led need to control. These children are often very charming and enigmatic. On the surface, to a stranger, they may seem like extremely polite, talkative and sociable children. However, parents are all too aware of how this sociability is very superficial; the child doesn't appear to understand where s/he fits in to the equation, sometimes thinking of him/herself as having the same status as an adult.

These children seem to have no real fear of authority figures, such as teachers or the police. They may prefer to converse with adults rather than their peers. They are often described as Jekyll and Hyde characters and seem to switch mood very quickly. They often have meltdowns and display extreme and sometimes violent behaviour. This should be viewed as a panic attack and often happens in response to further demands or even perceived demands.

Some children are able to manage at school (although their avoidance is usually just more subtle) but may blow-up at home. Some may be the opposite, displaying all their behaviour at school, while others may behave similarly in both situations.

Their ability to role play and their impaired empathy (rather than complete lack of empathy) is what appears to set them apart from those children and young people with more typical autism

disorders. This can be confusing for clinicians and those working with these children who are not familiar with the PDA diagnosis.

Characteristics of children with PDA

The Autism Education Trust, which is supported by the Government's Department for Education, produced the AET Guidelines for management of PDA which were directly taken from Phil Christie's 2007 paper (Good Autism Practice: The Distinctive Clinical and Educational Needs of children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice). Some of these points are discussed below. In order to manage a child with PDA, though, it is first worth looking at the characteristics of these children.

Problems interacting with the real world

Like other children with ASDs that have been managed poorly, those with PDA will often have low self-esteem and a great lack of confidence in attempting anything at all. At the same time, they may want to be able to do something straight away without realising the necessary effort required to get there.

Unusual responses to praise

Some children with PDA feel quite ambivalent about being praised (though that's not to say that praise cannot be given). For example, a child may rip up his or her work when it is commented on.

Inability to adapt to learning

Children with PDA sometimes seem not to easily "learn" from their experiences, which may be why a more traditional behavioural approach often fails.

Unpredictability

Similarly, these children may appear to be settled for periods of time and then

may appear to have a very unsettled phase, despite there being no particular change in their management. This can wrongly lead carers and teachers to assume the approach they are taking is at fault rather than believing it is part of the child's internal environment.

Mood swings and compulsive behaviour

Unfortunately, emotional regulation is very poor in children with PDA and they often blow-up very quickly and can display explosive, aggressive, violent and obscene or shocking behaviour. Consequently, their friendships may be difficult and whilst they often desire friendships, if they haven't frightened others off, they frequently sabotage the friendships by their persistent need to be in control, often appearing quite bossy, manipulating, refereeing and sometimes even victimising other children.

Detachment from reality

Some children with PDA have a very overactive imagination when it comes to role play and fantasy. This can be quite extreme and may be more prominent in girls than boys. It can be quite detrimental to their wellbeing as they can cut-off from reality, becoming another character completely.

Managing a child with PDA

Continuity of support

With these characteristics in mind, managing a child with PDA requires a highly individualised and flexible approach. The quality of the relationship with teachers and teaching assistants is paramount and the child may work better with some school staff than others. Making sure that this person keeps working with the child with PDA for as long as possible can be very beneficial, as long as the teacher is given good support themselves. In general,

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though, using a few staff members is likely to be healthier for everyone when the child is able to tolerate this.

Adapting the teaching style

Because of the child's resistance to demands, the carer or teacher needs to adopt a less directive style, rather than asking the child to do something or produce a piece of work. Using phrases like "I wonder how I might..." or "I wonder who could do this..." or even just leaving work/tasks to be found can be effective approaches for the child with PDA. Making a game out of a task – "let's see who can brush their teeth quickest; I'll race you", for example – can work well.

It can be a good idea to use rules, or even sometimes visual timetables, to depersonalise the demand; for example, "It's not me asking you to do this; it's the health and safety rule". Visual timetables can work in a similar way but they may need changing around more frequently than the usual "same lesson on Tuesdays" that might be needed for a more typically autistic child. Sometimes, using choices of tasks, making the task required the "best" option, is helpful. Allowing the child some control is key to reducing anxiety around demands. It is also worth remembering, though, that some days, if the child is extremely anxious, s/he may require there to be very few demands at all, while on other days tolerance levels are higher and demands can therefore be increased.

Embracing change

More typically autistic children would appear to benefit from routine and keeping things the same. With PDA, it is often more helpful to keep changing the routine, keeping things novel and exciting. Strategies that you find working in children with PDA might not work for very long and new ideas have to be thought up when existing practises are discovered not to work. This can be exhausting for parents and teachers but it can also be very rewarding when new strategies are found to be working where previous ones didn't.

A calm approach

Someone working with a child with PDA needs to be positive, yet calm, and stable in their emotions and must not just react to the behaviour but be able to gauge a child's level of anxiety and reduce demands as necessary throughout the day. This requires a great deal of flexibility, particularly from schools, in order to succeed.

Although these methods may appear quite untraditional, it is clear from reports from parents and teachers throughout the UK that children who fit the PDA profile respond best to these over other more traditional forms of management; the rewards of parenting and schooling a child with PDA can be immense. **SEN**

Further information

Margaret Duncan runs the PDA Contact Group (soon to be PDA Society) and is a parent of a child with PDA. She co-authored the book *Understanding Children with Pathological Demand Avoidance* (P. Christie, R. Fidler, M. Duncan and Z Healey). She is also a general practitioner in Sheffield: www.pdacontact.org.uk