

PDA: what is pathological demand avoidance syndrome?

Pathological demand avoidance syndrome is increasingly recognised as a diagnosis on the autism spectrum.

Margo Duncan from the PDA Contact Group explains more about the condition.

BY MARGO DUNCAN

THE CENTRAL DIFFICULTY for people with pathological demand avoidance (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.

A child or adult with PDA may already have been diagnosed as atypically autistic or as having pervasive developmental disorder not otherwise specified (PDD-NOS), or they may have a string of labels, including attention deficit disorder (ADD), autism spectrum disorder (ASD), behavioural difficulties and oppositional defiance disorder (ODD). Occasionally their parents have been wrongly told that the problem is a parenting issue.

What are the main features of PDA?

The first thing that parents notice is that their child just won't do anything that he or she is told to do. We are not talking about the usual disobedience you would expect from toddlers and young children – we're talking about

complete avoidance of almost any demand.

Children with PDA are often very anxious (this becomes more apparent as they get older) and this anxiety becomes much worse when they are not in control. The less control they have of a situation, and the more demands that are made of them, the more likely it is that their behaviour will escalate – sometimes into violent outbursts. Often, the demands that the child thinks are being made of them are only perceived demands, yet these can still cause high levels of anxiety about what they think might happen as a result of the demand.

Children with PDA can be quite socially skilled and are usually very controlling with their parents, peers, and almost everyone else, including figures of authority. Sometimes their parents describe them as a mini adult or say that they 'think they're an adult'.

Children with PDA often have multiple sensory difficulties, much like other people who are diagnosed on the autism spectrum. Sometimes they form obsessions with certain people and they may also have →



People with PDA may avoid real and perceived demands

→ other neurological features such as tics, fits or clumsiness. They often experience an early speech or language delay but they frequently catch up as they grow a little older. Sometimes, children with PDA can role play to an extreme degree, believing that they are a different person or animal character and acting like them for days.

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.

What if you suspect that you or your child has PDA?

If you think that you or your child may have PDA, you need to find a professional who knows enough about the condition (or is prepared to find out). The Elizabeth Newson Centre in

Nottingham (part of the autism charity NORSACA) is where diagnosis began in the UK. This centre dates back to the 1980s, when Professor Elizabeth Newson coined the term 'pathological demand avoidance' to describe the behaviour of the children she was meeting. The centre still carries out comprehensive assessments of children and diagnoses other autism spectrum disorders too. As yet there are no specific centres diagnosing adults with PDA. The PDA Contact Group can help with finding a clinician in your area for a child, and can give you information and parent-to-parent support through its online forum.

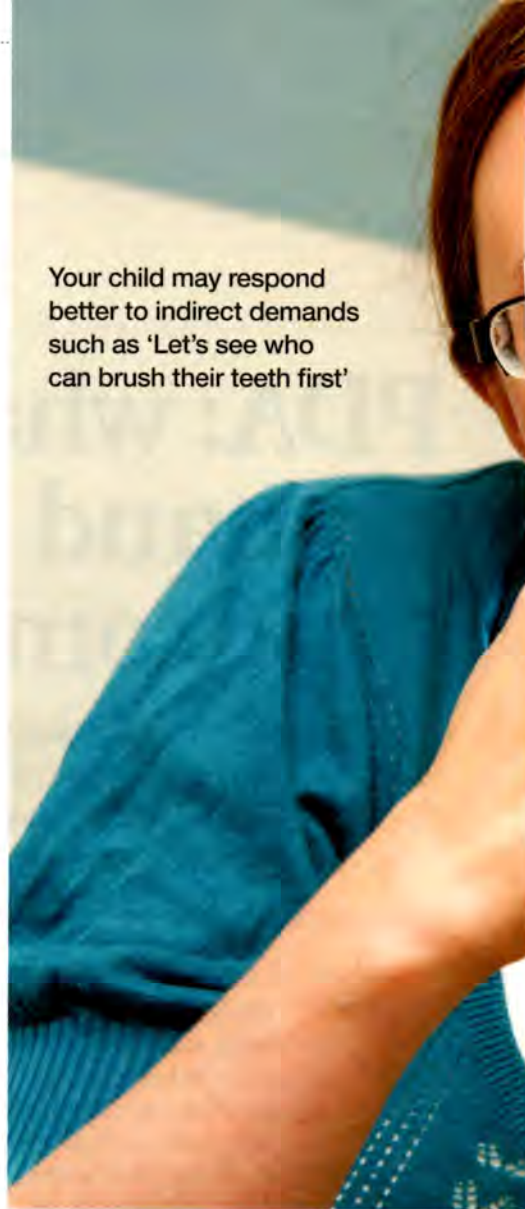
Having a diagnosis of PDA is helpful for a number of reasons.

- 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 in a high exclusion rate unless sufficient support is provided.

How can you support a child with PDA?

Supporting children with PDA presents a huge challenge. It is not uncommon for these children to suffer multiple exclusions from school, or for their parents to be sent to parenting classes (despite having other children who they have had no problems with). Many families struggle to cope with the stress of living with a child with PDA.

But although this syndrome



Your child may respond better to indirect demands such as 'Let's see who can brush their teeth first'

has taken a long time to become recognised, it is now being taken seriously by some clinicians. Despite it not being in the diagnostic manuals, some doctors and diagnosticians are choosing to use the term because of the helpful management strategies that can be introduced as a result.

Parents generally do not want a 'label' and hate being accused by doctors of wanting to label their child, but using the term PDA positively can help a child on the right path to education and better support at home.

The approach to supporting children with PDA is different to that which you might use when supporting children with other diagnoses on the autism spectrum. Whereas direct instructions might be appropriate for most children with autism (eg 'Brush your teeth'), children with PDA don't usually respond well to direct demands. They tend to respond much better to a more indirect approach, such as 'Let's have a race and



see who can brush their teeth first'.

Other helpful strategies include offering your child choices instead of single requests, using humour and excitement and trying to recognise the particular situations or experiences that make them anxious. But reducing the number of demands placed on your child whilst also maintaining boundaries can be a difficult thing to balance, so

parents may need support with this (see sources of support below).

In the classroom, teachers may find it necessary to adopt a flexible approach. They need to gauge the child's anxiety level and determine how many or which demands can be made. Again, making indirect demands can be an effective way for teachers to overcome the child's anxiety. ●

→ Find out more

The PDA Contact Group and Forum

Affiliated to Contact a Family, this group offers support, advice and information to anyone involved with a person diagnosed with PDA, child or adult. Support Line: 0114 258 9670
Web: www.pdacontact.org.uk
@PDAcontactgroup

NORSACA

For literature about PDA and information

about the Elizabeth Newson Centre.
www.norsaca.org.uk.

The PDA Resource

An independent website featuring many resources and useful links.
www.thePDAresource.com.

The National Autistic Society

Our website features information on PDA at www.autism.org.uk/pda.



PDA: the main features

- Passive early history in the first year.
- Continues to resist and avoid the ordinary demands of life, using socially manipulative strategies.
- Surface sociability but apparent lack of social identity.
- Mood swings, impulsive behaviour and led by a need to control.
- Comfortable (sometimes to an extreme extent) in role play and pretend play.
- Early language delay.
- Obsessive behaviour.
- There may be neurological signs such as clumsiness and physical awkwardness.