



Cerebra

Positively Different

Pathological Demand Avoidance Syndrome (PDA)

What is Pathological Demand Avoidance Syndrome (PDA)?

PDA is a pervasive developmental disorder separate from, but related to autism, first identified by Professor Elizabeth Newson at the University of Nottingham in 1983.^{1,3} The diagnosis of PDA is currently not recognised in the DSM-IV or ICD-10.⁶ It is a lifelong disability and, as with autism and Asperger's syndrome, people with PDA will require different amounts of support depending on how their condition affects them. People with PDA will avoid demands made by others, due to their high anxiety levels when they feel that they are not in control.^{1,2,4}

People with PDA can be controlling and dominating, especially when they feel anxious and are not in charge. Many parents describe their PDA child as a 'Jekyll and Hyde' character.^{1,5} It is important to recognise that these children have a hidden disability and often appear 'normal' to others.

Individuals with PDA are typically socially manipulative with people, and are thus superficially socially skilled, which sets them apart from those with autism and Asperger's syndrome.⁴

People with PDA tend to have much better social communication and interaction skills compared to other people on the autism spectrum.¹ However, individuals with PDA still have significant difficulties in these areas, usually because they need to control the interaction. They often have highly developed social mimicry and role play, sometimes becoming different characters or personas.¹

Who is affected?

Unlike autism and Asperger's syndrome, both of which seem to affect more boys than girls, PDA affects boys and girls equally.^{1,2} 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

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with ASD.^{1,2} As more diagnoses of PDA are made, prevalence figures will become more apparent.

Characteristics

The main features of PDA are:

- obsessively resisting ordinary demands
- appearing sociable on the surface but lacking depth of understanding
- excessive mood swings, often changing 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.¹

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 ASD but when the avoidance reaches pathological levels, major difficulties arise.

The following are the defining criteria for PDA.

1. Passive early history in first year

The child often drops toys and 'just watches'. As more is expected of them, the child becomes 'actively passive', i.e. strongly objects to normal demands, resists. A few actively resist from the start, everything is on their own terms.^{3,4,6}

2. Resisting demands obsessively

This is the main criterion for diagnosis. People with PDA become experts at avoiding demands. They seem to feel an enormous amount of pressure from ordinary expectations.^{1,2} It is often not the activity itself that is a pressure but the fact that another person is expecting them to do it.^{1,2} The person's tolerance can vary from day to day, or moment to moment. The more anxious a person with PDA is, the less they will be able to tolerate demands.

As a child, their avoidance can know no boundaries and usually includes a level of social manipulation.^{1,2,3} Strategies range from:

- simple refusal
- physically incapacitating self: hides under table, curls up in corner, goes limp, dissolves in tears, drops everything, seems unable to look in direction of task (though retains eye contact), removes clothes or glasses, 'I'm too hot', 'I'm too tired', 'It's too late now'
- distraction, e.g. 'Look out of the window!' 'I've got you a flower!' 'I'm going to be sick'
- giving excuses e.g. 'I'm sorry, but I can't' 'I've got to do this first' 'can't make me'
- delaying
- arguing
- suggesting alternatives
- reducing meaningful conversation: bombards adult with speech (or other noises, e.g. humming) to drown out demands; mimics purposefully; refuses to speak
- withdrawing into fantasy: talks only to doll or to inanimate objects, growls, bites
- outbursts, screaming, hitting, kicking; best construed as panic attack
- if forced to comply, they may become verbally or physically aggressive with severe behavioural outbursts, best described as a 'panic attack'.^{1,3,4,6}

3. Surface sociability

People with PDA are often very sociable and can display degrees of empathy previously not thought to be consistent with autism.^{1,4} Sometimes it seems that they are able to understand other people at an intellectual level but not at an emotional one.¹ Yet, their social interaction is often flawed by their inability to see the bigger picture, their lack of boundaries and their desire to be in control of the situation.^{1,3} They often understand rules but do not feel they apply to themselves. This can lead to playground peer group difficulties. On the surface the child is sociable, but there is an apparent lack of social identity, pride or shame.^{2,4}

Children with PDA appear to identify with other children but tend to have no sense of responsibility and are not concerned with what is 'fitting to their age'.^{2,3} Praise and punishment is ineffective and there seems to be no

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4. Excessive mood swings

People with PDA may switch from one state to another very quickly, driven by the need to be in charge.^{1,2} This is often in response to perceived expectations.¹ Many individuals appear continually on the edge of violence or loud excitability. They may apologise but repeat their behaviour at once, or totally deny the obvious.³ Rules and routine do not tend to help individuals with PDA and they are generally better with variety and novelty.^{2,6}

5. Comfortable 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's syndrome.¹ Generally, people with PDA are very good at taking on the roles and styles of others.^{1,2,4} In extreme cases, children can become so engrossed in this role-playing that they lose touch with reality.^{1,2,3,4}

6. Language delay, seemingly as a result of passivity

Children with PDA may have some language delays at an early age, however there is often a sudden degree of catch-up.^{1,2,3,4} Certain elements of communication are not as disordered as in autism or Asperger's syndrome, and they have more fluent use of eye contact and better conversational timing. Individuals may still experience some difficulties such as taking things literally and misunderstanding sarcasm and teasing.¹ As an extreme form of avoidance, some children become selectively mute in certain situations.¹

7. Obsessive behaviour

Obsessions will vary from person to person but are often social in nature.^{1,3,4} Sometimes, obsessions with particular people can become problematic and overbearing for those who are on the receiving end.^{1,2,6}

8. Neurological involvement

There can be soft neurological signs: clumsiness, awkwardness and many children

are slow to crawl or never crawl.^{2,3,4,6} Most show barely controlled excitability and impulsivity.^{2,3}

Other related characteristics

Sensory sensitivities

Similarly to autism and Asperger's syndrome, people with PDA can often experience over- or under-sensitivity in any of their senses: sight, smell, taste, touch or hearing.¹

Other disorders

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. The apparent verbal fluency of people with PDA can sometimes disguise genuine difficulties in understanding. Before being diagnosed with PDA, some people will have already been diagnosed with autism, ASD, Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) or Atypical autism.¹

Severe behavioural difficulties

Many people with PDA have difficulty controlling their temper. As children, this can take the form of tantrums and violent outbursts. These outbursts are extreme anxiety or 'panic attacks' and should be treated with reassurance, calming strategies and de-escalation techniques. This behaviour can result in exclusion from school. For some children, this anxiety can develop to such an extent that they become school refusers or school phobic.¹

The behaviours listed above cause problems in many social contexts, during home and school life. Children with PDA differ from children with autism and other autism spectrum disorders.

They:

- may not be popular with their peers
- do not elicit sympathy
- have a limited supply of humour and shame for teachers and parents to use

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Children with PDA usually under-achieve in school compared with what is perceived as their 'true' potential. Some children try to keep a low profile, trying to blend in to avoid any attention being drawn to them, and this has been described by some as the 'Camouflage Effect'. However, when they receive unwanted attention, they may become actively disruptive.

as a tool

- will try to shock – and if this works, they will do it again
- will mimic others and will often become the class scapegoat
- will not be able to handle these situations and may often end each episode or confrontation with an outburst
- often show no respect for 'authority'.³

Because of their social identity problems, problems in many social contexts can occur, at home and school. To all intents and purposes they may seem to become compliant and well-behaved but this may be a 'role' children with PDA take on to be left alone.³

School

Children with PDA usually under-achieve in school, compared with what is perceived as their 'true' potential.⁴ Some children try to keep a low profile, trying to blend in to avoid any attention being drawn to them, and this has been described by some as the 'Camouflage Effect'.⁴ However, when they receive unwanted attention they may become actively disruptive. Some children may become aggressive as another way of stopping imminent demands.

These two types of PDA behaviour both appear anxiety-induced and might be described as 'actively passive' to 'actively disruptive'.⁴ Some children move from one type of behaviour to another at different ages.⁴ It is important to remember that these children do not choose to behave in these ways. It is their inability to cope with what they perceive as the stress of everyday demands that manifests itself differently according to their individual personalities, and possibly, underlying cognitive deficits and neurological pathologies.⁴

Parents

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 need a lot of support themselves, as their children can often present severe behavioural challenges.¹

What causes PDA?

The exact cause of PDA is still being investigated.¹ It is likely to be caused by a

combination of factors, genetic and environmental, which may account for changes in brain development. ¹ The underlying cause of PDA is believed to be organic brain dysfunction with genetic factors. ²

It seems likely that the genetic factors are similar to those in autism, but refer to inheritance of a pervasive developmental disorder rather than PDA specifically. Approximately 6% of children with PDA are known to have a sibling with either PDA or autism/Asperger's syndrome. Preliminary research is currently underway. ²

It is important to remember that PDA is not caused by a person's upbringing or their social circumstances.

Diagnosis

A diagnosis is the formal identification of PDA, usually by a professional such as a paediatrician, psychologist or psychiatrist. ¹ Children may not be diagnosed until they are older due to recognition of PDA as a condition being fairly recent, and the apparent social abilities of many children with PDA may mask their problems. ¹ They may already have had a suggested diagnosis of autism or Asperger's syndrome. It is usually due to the individual's surface sociability and vivid imagination that confusion arises amongst professionals regarding the ASD diagnosis. ¹

A provisional diagnosis is possible before the age of four. ² However diagnosis is more difficult than in autism because the child usually shows more social interest, normal language development and better imaginative play by age four or five than autistic children do. ²

The National Autistic Society ¹ explains that 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,

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PDA children may be compliant at school and often behave much worse at home. It is important for teachers and parents to realise that this is not due to less competent handling, but simply because these children have reached their 'tolerance limits' and need to 'let their hair down'.

- It warns local authorities that this diagnosis can sometimes result in a high likelihood of exclusion from school, unless sufficient support is provided.

To get a diagnosis, a GP referral to a local paediatrician who specialises in autism spectrum disorders may be sufficient. Advice can be offered by the Elizabeth Newson Centre, part of Sutherland House Children's Services. See contact details at the end of the paper.¹

Treatment

It is important to remember that despite the behaviour these children may sometimes exhibit, they are vulnerable characters. Pushing a PDA child to obey demands is likely to lead to high anxiety and 'meltdown' behaviour or panic attacks.^{4,5} These children need reassurance and not blame, as the child cannot help this behaviour.⁵

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Knowledge about appropriate interventions and educational approaches is growing. It is important to distinguish PDA from other conditions, to ensure that the child receives the correct educational approach. It is important to diagnose them separately since they do not respond well to the educational and treatment methods that are helpful with autistic and Asperger's children. Overall, best practice differs between children with PDA and children with autism.^{4,5}

People with PDA tend to respond much better to a more indirect and negotiative style that allows them to feel in control.¹ Appropriate guidelines for education and handling are now available from the Early Years Diagnostic Centre (PDA Contact group listed at end of paper). These are entitled 'Educational and Handling Guidelines for Children with Pathological Demand Avoidance Syndrome' and can be found at <http://www.pdacontact.org.uk/frames/index.html?guidelines.shtml>

Advice when dealing with children with PDA:

- provide good role models

- provide clear boundaries
- handling should be indirect: no confrontation
- routine and sameness do not work (unlike autism and Asperger Syndrome)
- soften your firmness with humour
- be flexible and imaginative
- see 'aggressive' behaviours as anxiety/panic attacks - reassure rather than blame.
- keep the child on task
- check repeatedly and over time that what the child appears to be learning is being absorbed
- ensure minimum degree of disruption to others in the class
- try to promote good peer relationships
- a keyworker approach involving a minimum of 1:2 staff: pupils is the ideal.³

Organisations

- [NAS Autism Helpline](#)

Offers confidential information and advice on autism and related issues.

Web: <http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=10>

Email: autismhelpline@nas.org.uk

Tel: 0845 070 4004 open 10am-4pm, Monday-Friday

- [The PDA Contact Group](#)

A group for parents of children with PDA which is part of Contact a Family. The website was established in 1997 and features information about PDA and its history, as well as support advice for home and school. Also includes an online support forum. The group is in touch with over 500 families and is rapidly growing.

Web: <http://www.pdacontact.org.uk>

Support Forum: <http://ccgi.pdacontact.org.uk/forum/index.php>

E-mail: margaret.duncan@pdacontact.org.uk or margoduncan@googlemail.com

Tel: 020 7608 8700 Admin

Tel: 0114 2589 670 (Margaret Duncan, National Coordinator for the group)

Calls are preferred after 8pm, or leave an answerphone message.

- [The Elizabeth Newson Centre](#)

Advice, support, training and a range of publications are available through the Elizabeth Newson Centre, part of NORSACA's Sutherland House Children's Services in Nottingham. The Elizabeth Newson Centre (NORSACA) provides a range of conferences and events for both professionals and parents. It also has a publications list that has a number of papers on PDA. The centre can also provide training for schools and other organisations across the UK.

Web: <http://www.norsaca.org.uk> or <http://www.sutherlandhouse.org.uk>
Email: norsacaadmin@btconnect.com
Tel: 0115 976 1805

- **The Maze Group**

The Maze in Nottingham offers a drop-in centre providing support and advice for parents, and training in autism and PDA.

Web: <http://www.themazegroup.org/>
Email: admin@themazegroup.org
Tel: 0115 9205800

- **Contact a Family**

If your child has a rare disorder or a learning disability, CAF can help with information and support groups.

Web: www.cafamily.org.uk
Email: info@cafamily.org.uk
Tel: 0808 8083555

Reading

- **Children with Pathological Demand Avoidance Syndrome: a booklet for brothers and sisters.**

Author: Julie Davies

Available from the Elizabeth Newson Centre.

- **Educational and Handling Guidelines for Children with Pathological Demand Avoidance Syndrome.**

Author: Professor Elizabeth Newson



Available from the Elizabeth Newson Centre.

This information is not meant to replace the advice of any physician or qualified health professional. The information provided by Cerebra is for information purposes only and is not a substitute for medical advice or treatment for any medical condition. You should promptly seek professional medical assistance if you have concerns regarding any health issue.

References

- ¹ NAS (2008) Pathological Demand Avoidance Syndrome (PDA). [online] NAS. Available from: <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1581&a=17634>. [Accessed 5 January 2010]
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- ⁵ TES (2009) A Teacher's Guide to Understanding Pathological Demand Avoidance Syndrome (PDA). [online]. TES. Accessed from: <http://www.tes.co.uk/article.aspx?storycode=6016184>. [Accessed 7 January 2010]
- ⁶ Yapko, D. (2003) Understanding Autistic Spectrum Disorders: Frequently Asked Questions. [e-book] Gateshead : Athenaeum Press. Available from: http://books.google.co.uk/books?id=TfoXRdTeUnkC&pg=PA57&lpg=PA57&dq=pathological+demand+avoidance&source=bl&ots=S7eDgPrb6y&sig=vR2QamGGHJW8j8FA5IWEb5u-m0Y&hl=en&ei=P8BiS96zH5SSjAf3uv2iBw&sa=X&oi=book_result&ct=result&resnum=7&ved=0CBcQ6AEwBjgo#v=onepage&q=pathological%20demand%20avoidance&f=false. [Accessed 29 January 2010]

The Cerebra In-house Research Team carries out desk-based research into a number of areas, based upon parent and professional requests, new scientific evidence and issues raised by our staff. We aim to provide information that is relevant to parents and carers of children with disabilities as well as the professionals who come into contact with them. By empowering parents and professionals with knowledge, we can help them to improve the lives of the children they care for and support.

If you require further information or would like to suggest avenues for further research, please get in touch.

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For Brain Injured Children & Young People

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The findings of this report are those of the author, not necessarily those of Cerebra.