

Pathological Demand Avoidance (PDA)

Pathological Demand Avoidance (PDA), first described by Professor Elizabeth Newson at the University of Nottingham in 1983 as a pervasive developmental disorder distinct from autism, it is increasingly becoming recognised as part of the autistic spectrum. Children with this syndrome resist and avoid all the 'demands' that are made on them during their normal daily life. The disorder appears to be shared equally between girls and boys, compared with autism (about 1 in 4 is a girl) and Asperger Syndrome (less than 1 in 10). A provisional diagnosis may be possible at around the age of four, but this is not easy. The child will show more social interest, imaginative skills and normal language development than a child with autism.

When Professor Newson first started writing about PDA, she described it as a **"failure to code social identity and hence social obligation"**. This compares with her description of autism as a "failure to code all first communicative modes: speech, gesture, facial expression, other body language, and the timing of these"; dysphasia: a "failure to code spoken messages"; dyslexia: a "failure to code written messages".

The Diagnostic Criteria of PDA: (see www.pdacontact.org.uk for a comparison with autism / Asperger Syndrome)

- (As last resort) Outbursts, screaming, hitting, kicking; best construed as panic attack.

1. Passive Early History in first year

Often doesn't reach, drops toys, 'just watches'; often delayed milestones. As more is expected of him/her, 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. Parents tend to adapt so completely that they are unprepared for the extent of failure once a child is subjected to ordinary group demands of nursery or school; they realise their child needs 'velvet gloves' but don't perceive it as abnormal. Professionals too see the child as puzzling but normal at first.

2. Continues to resist and avoid ordinary demands of life

Seems to feel under intolerable pressure from normal expectations of young children; devotes self to actively avoiding these. Demand avoidance may seem the greatest social and cognitive skill, and most obsessional preoccupation. As language develops, strategies of avoidance are essentially socially manipulative, often adapted to adult involved; they may include:

- Distracting adult: e.g. 'Look out of the window!' 'I've got you a flower!' 'I'm going to be sick'
- Acknowledging demand but excusing self: e.g. 'I'm sorry, but I can't' 'I've got to do this first' 'can't make me'
- 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' 'I'm handicapped' 'my hands have gone flat'
- Withdrawing into fantasy, doll play, animal play: talks only to doll or to inanimate objects; appeals to doll, 'My girls won't let me do that' 'But I'm a tractor, tractors don't have hands'; growls, bites.
- Reducing meaningful conversation: bombards adult with speech (or other noises, e.g. humming) to drown out demands; mimics purposefully; refuses to speak.

3. Surface sociability, but apparent lack of sense of social identity, pride or shame

At first sight normally sociable (has enough empathy to manipulate adults as shown in 2. but ambiguous (see 4) and without depth. No negotiation with other children, doesn't identify with children as a category: the question 'Does she know she's a child?' makes sense to parents, who recognise this as a major problem. Wants other children to admire, but usually shocks them by complete lack of boundaries. No sense of responsibility, not concerned with what is 'fitting to her age' (might pick fight with toddler). Despite social awareness, behaviour is uninhibited, e.g. unprovoked aggression, extreme giggling/inappropriate laughter or kicking/screaming in shop or classroom. Prefers adults but doesn't recognise their status. Seems very naughty, but parents say 'not naughty but confused' and 'it's not that she can't or won't, but she can't help it' - parents at a loss, as are others. Praise, reward, reproof and punishment ineffective; behavioural approaches fail.

4. Liability of Mood, impulsive, led by need to control

Switches from cuddling to thumping for no obvious reason; or both at once ('I hate you' while hugging, nipping while handholding). Very impetuous, has to follow impulse. Switching of mood may be response to perceived pressure; goes 'over the top' in protest or in fear reaction, or even in affection; emotions may seem like an 'act'. Activity must be on child's terms; can change mind in an instant if suspects someone else is exerting control. May apologise but re-offend at once, or totally deny the obvious. Teachers need great variety of strategies, not rule-based: novelty helps.

5. Comfortable in role play and pretending

Some appear to lose touch with reality. May take over second-hand roles as a convenient 'way of being', i.e. coping strategy. Many behave to other children like the teacher (thus seem bossy); may mimic and extend styles to suit mood, or to control events or people. Parents

are often confused about 'who he really is'. May take charge of assessment in role of

psychologist, or using puppets, which helps co-operation; may adopt style of baby, or of video character. Role play of 'good person' may help in school, but may divert attention from underachievement. Enjoys dolls/toy animals/domestic play. Copes with normal conventions of shared pretending. Indirect instruction helps.

6. Language delay, seems result of passivity

Good degree of catch-up, often sudden. Pragmatics not deeply disordered, good eye-contact (sometimes over-strong); social timing fair except when interrupted by avoidance; facial expression usually normal or over-vivacious. However, speech content usually odd or bizarre, even discounting demand-avoidant speech. Social mimicry more common than video mimicry; brief echoing in some. Repetitive questions used for distraction, but may signal panic.

7. Obsessive behaviour

Much or most of the behaviour described is carried out in an obsessive way, especially demand avoidance: as a result, most children show very low level achievement in school because motivation to avoid demands is so sustained, and because the child knows no boundaries to avoidance. Other obsessions tend to be social, i.e. to do with people and their characteristics; some obsessively blame or harass people they don't like, or are overpowering in their liking for certain people; children may target other individual children.

8. Neurological Involvement

Soft neurological signs are seen in the form of clumsiness and physical awkwardness; crawling late or absent in more than half. Some have absences, fits or episodic dyscontrol or apparent generalised over-arousal.

Problems: The behaviours listed above are going to cause problems in many social contexts, during home and school life. These children are different from children with autism and other autism spectrum disorders. They may not be popular with their peers and may not elicit sympathy; they have a limited supply of humour and shame for teachers and parents to use as a tool. They will try to shock you – and if this works, they will do it again. They will mimic you and others and will often become the class scapegoat. They will not be able to handle these situations and may often end each episode or confrontation with an outburst. They have no respect for 'authority'. Because of their social identity problems, they see no difference between adult/child, teacher/pupil. As they fail to commit to the other children in their year group, they will tend to lean towards you, the adult. To all intents and purposes they may seem to become compliant and well behaved: but this may be a 'role' they are playing because it produces the right result as far as they are concerned: they are left alone.

Remember:

- she needs good role models
- she needs clear boundaries
- handling should be indirect: do not confront
- routine and sameness do not work (unlike autism and Asperger Syndrome)
- soften your firmness with humour
- be flexible and imaginative – what works today might not work tomorrow ... but may next week!

- see 'aggressive' behaviours/outbursts as anxiety/panic attacks: reassure rather than blame
- if she manages to control herself while at school, she will 'blow' when at home, either verbally or physically. And sometimes vice versa.

Professor Newson recommends -

1. keep her on task
2. check repeatedly and over time that what she appears to be learning is being absorbed
3. ensure minimum degree of disruption to others in the class
4. try to promote good peer relationships
5. a keyworker approach involving a minimum of 1:2 staff: pupils are the ideal.

Useful Contacts:

The PDA Contact Group offers support, advice, information and contact with other parents. Also has an informative website and an online forum, providing advice and information for parents & professionals.

Web: www.pdacontact.org.uk

E-mail: margaret.duncan@pdacontact.org.uk

Tel: 0114 258 9670

The National Autistic Society has an information sheet on PDA which can be found at <http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1581&a=17634>. They are the largest autism charity in the UK and can help with local support groups; information for individuals, parents, professionals; befriending; training; links and much more.

Web: www.nas.org.uk

Helpline: 0845 070 4004 (10am-4pm)

Contact a Family 209-211 City Road, London EC1V 1JN. 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

The Elizabeth Newson Centre (under umbrella of NORSACA)

Tel: 01623 490879

Tel: 01623 490879

Sutherland House Children's Services, 272 Longdale Lane, Ravenshead, Notts NG15 9AH. An assessment and diagnostic centre with particular experience in PDA. Also produces its own publications, useful articles and booklets on PDA, autism and other disorders

Web: www.sutherlandhouse.org.uk

E-mail: diagnostic-centre@sutherlandhouse.org.uk

Reading

Children with Pathological Demand Avoidance Syndrome: a booklet for brothers and sisters, author: Julie Davies, available from the Elizabeth Newson Centre (see above).

Educational and Handling Guidelines for Children with Pathological Demand Avoidance Syndrome is a paper by Professor Elizabeth Newson available from the Elizabeth Newson Centre (see above).

Note: This OAASIS Information Sheet uses 'she' and 'her' rather than the cumbersome 'he / she' 'his / her' 'him / her'. No sexism is intended. The sheets are checked annually; please ensure you have the current version.

Acknowledgements: This Information Sheet has been produced using Prof Elizabeth Newson's papers as displayed on the PDA Contact Group website, with her full permission.

OAASIS publications

- SEN Information Sheets
- First Guide to ...
- Cards explaining 9 learning disabilities
- Legal advice Information Sheets
- SEN 'How to' guides

All OAASIS publications can be downloaded from www.oaasis.co.uk