

A Few Golden Rules: Strategies that might help at home

- **Choose your battles carefully**

Focus on a few important boundaries like safety issues. Learn to 'let go' of things that are not important. Consider: is it worth a meltdown?

- **Balance tolerance and demands**

Every day is different for children with PDA. When anxiety is high, demands should be few. When your child is more relaxed, demands can be increased.

- **Don't take it personally**

Children with PDA are driven by anxiety. They can say and do things that are hurtful. Understand that the 'root cause' of this behaviour is their high anxiety.

- **Use indirect demands**

Challenges are great for getting things done. For example, "Race you to the bathroom – bet I can wash my face before you!"

- **Offer limited choices to give the child SOME control.**

For example saying "do you want to have a bath or a shower?" communicates the need to wash but offers a choice, which helps to reduce anxiety.

You can find more strategies on the PDA Society website



Do you suspect your child has PDA?

Has your child been recently diagnosed with the condition?

The National Autistic Society (NAS) website has a useful guide to PDA, which can be given to family members, teachers and other professionals who may be involved in supporting your child. Search for 'PDA' on the NAS website.

www.autism.org.uk

You can find more advice and support via the PDA Society website, for example:

- Seeking a diagnosis
- Information on managing meltdowns
- Books and other resources
- Lists of external websites, Facebook groups, blogs and interesting articles
- A forum with private message boards which are accessible to parent members only

Find us at:

www.pdasociety.org.uk



A Parent's Guide to Understanding Pathological Demand Avoidance Syndrome (PDA)



What is Pathological Demand Avoidance?

“PDA is best understood as an anxiety driven need to be in control and avoid other people’s demands and expectations.”

Understanding Pathological Demand Avoidance syndrome in children. Christie, Duncan, Fidler & Healey (2011).

Pathological Demand Avoidance (PDA) is a lifelong neurological condition and an Autism Spectrum Disorder (ASD); which was first identified by Professor Elizabeth Newson in the 1980’s. People with PDA experience extreme levels of anxiety in response to everyday social pressures, demands and expectations.

Simple tasks such as being asked to get dressed, eat a meal at the table, and go out -even to an enjoyable place like the cinema - can be very challenging for a child with PDA. They will often go to great lengths to avoid demands – this is what is meant by the word, ‘pathological’.

A child with PDA might avoid demands in lots of different ways from simply refusing, making an excuse, delaying, withdrawing, distracting, negotiating, doing or saying something shocking, blaming or even displaying challenging and extreme forms of behaviour such as screaming, swearing, trashing and smashing things or physically attacking another person.

‘Meltdowns’ can happen very suddenly and are distressing for the parent but especially for the child. When this happens, the child is at a genuine ‘crisis point’ and in a state of ‘panic’. They will not be able to reason and may not even be able to remember anything about the event afterwards. Meltdowns can last for a very long time, sometimes several hours and are not like a typically developing child throwing a tantrum.

What does a child with PDA look like?

Children with PDA look like other children. They often make good eye contact and are very likeable – sociable and chatty. They can have a real charm and charisma; be affectionate, determined, creative, passionate and focused on things that interest them, have a vivid imagination and enjoy humour.

They have many strengths and qualities that can be used to capture their interest and help them.

Children with PDA experience the same difficulties as other children on the autism spectrum, including sensory issues, but their social understanding and communication skills may seem more advanced on the surface. They may have other conditions alongside PDA, for example Dyslexia, Dyspraxia or Attention Deficit Hyperactivity Disorder (ADHD).

The difficulties that children with PDA have can be very subtle, even to doctors and teachers. This makes others think that they are managing but often they are not.

As the child grows older and become more self-aware, they can learn to manage their emotions better. This means that outbursts become fewer.

If you suspect your child has PDA, it is important to learn as much as you can about the condition and practice the strategies and techniques overleaf that will help to reduce their anxiety.



How do I tell if my child has PDA?

The characteristics of PDA are :

- Resisting and avoiding ordinary demands
- Appearing sociable but lacking depth in understanding
- Excessive mood swings and impulsivity
- Comfortable in role play and pretend, sometimes to an extreme extent
- Language delay, with a good degree of catch-up
- Obsessive behaviour, often focused on real or imagined people.

Why does my child have PDA?

Parenting a child with PDA can be a very challenging experience. It can have a huge impact on the rest of the family, especially siblings *BUT...*

PDA is NOT the fault of the child with the condition, nor is it because of poor parenting or where you live. Rather, it is about a child with an ‘invisible disability’ trying hard to fit into a world they find confusing and frightening but long to be a part of.

The cause of PDA is still unclear but research is being carried out.