

PARENT RESOURCES

Pathological Demand Avoidance (PDA)

Pathological Demand Avoidance (PDA) is a condition which is part of the Autism Spectrum and is characterised by an overwhelming need to avoid or resist demands. AVOIDANCE of ordinary demands is the primary and most deliberating characteristic of PDA. It's driven by the child's uncontrolled ANXIETY, which can feel like a PANIC ATTACK.

Realising the anxiety comes from the demands makes things a bit easier to understand, although not necessarily easier to deal with, as it challenges the traditional parenting methods which do not work for a child with PDA.

HOW WILL MY CHILD MANAGE AT SCHOOL?

Children with PDA often have problems with their behaviour at school, and the condition can negatively affect a child's academic progress.

It is advisable to have a discussion with our Special Educational Needs Coordinator (SENCo) in order to highlight any concerns you may have. They will be able to assess your child's individual needs and design a bespoke programme of support.

In some circumstances, we may suggest an application should be made for an Education Health Care Plan (EHCP) in order to provide emotional support for your child.

The school has a toolkit of strategies to help support children with PDA.

Children with PDA find being asked to do things, even simple everyday things, extremely difficult. They try to avoid these demands. All children do this to some extent, of course, but these children do this much more than is considered normal. This is why it is called pathological.

In order to avoid these made of them, children with PDA will come up with all sorts of excuses:

"I'm too Cold" / "I'm too hot" / "I'm too poorly" / "I'm bored" "Just a minute..." / "Look over there..."

They may become very cross, agitated or aggressive if these demands are pursued; they have a meltdown.



PARENT RESOURCES

Pathological Demand Avoidance (PDA)

ALLOW THE OPTION OF SAYING NO

A child with PDA needs to feel they have some control. Using non-negotiable words gives the impression that you have made a decision for them and taken away their control. Avoid using 'demand' words such as:

- Need
- Must/Must not
- Can't
- Now
- Will/won't
- By (a time/date)

Many of these avoidance techniques require adequate social and language skills. Children with PDA may appear to be verbally competent, but may understand less than we think. Although they may be highly sociable, they usually struggle to understand where they fit in socially and their need to be in control can mean that their peer relationships can be challenging.

The other key area of difference is that children with PDA are often highly skilled when it comes to role play. They may become easily engrossed in fantasy to the point where they become certain characters and confuse pretending with reality. Some research has described this as a coping mechanism because it is a barrier to outside demands.

IMPORTANT POINTS

1. Develop a strong relationship

It is important to develop a strong relationship with a child who has high anxiety. The more you understand them, the easier it will be to distract them from potential crisis, and make you feel confident in how best to diffuse a situation.

2. Prepare the child ahead of time

Children with PDA find it helpful to know what is going to happen, as this gives them a sense of being in control, as well as allowing them processing time.

For some children, displaying information in a visual format can create a sense of independence and choice which reduces anxiety e.g. visual timetables can be made with the child and used to help the child understand what is happening. It is important to use these in a flexible and non-confrontational way, and that they are created and referred to with the child, rather than being done to the child. Children may like to draw their own symbols.



PARENT RESOURCES

Pathological Demand Avoidance (PDA)

3. Monitor signs of anxiety

The mood and behaviour of children with PDA can change very quickly. It is important to monitor for signs of increased anxiety, which can be reduced by decreasing demands. It can be particularly helpful to step back when the child is coping well, but be available nearby to intervene if the child becomes anxious. At the first signs of stress, it's a good idea to scale back the demands on the child.

As the child gets older, it's important to encourage them to begin to identify their own stress levels and what they need, and to teach them the skills to communicate this. A feelings board is a quick and useful aid to this. This can be available to children on the wall, and they can place their photo or name by the feeling which best matches their mood, and choose what they need.

4. Create space

Children with PDA find it hard to regulate their feelings. Make sure there's safe space at home — maybe a small tent or a bean bag with a 'Calm Box' that has a variety of sensory objects, such as playdough, stress balls, bubbles, soft fabrics, to encourage the child to self-soothe and regulate their emotions when they are feeling sad, cross, angry, anxious etc.

5. Keep calm

When children with PDA panic, they need the adults around them to stay calm. We must regulate ourselves first, so that we can then help the child to regulate their anxiety.

STRATEGIES FOR PDA

- Be flexible be prepared to adjust the goalposts. The end point does not need to be the same as the start point.
- Establish a relationship built on trust and a sense of fairness.
- It is important to remain calm.
- Try to ignore negative behaviours. Pick your battles!
- Focus on and enjoy their interests and strengths, use this to motivate the child.
- Avoid direct instructions for example, 'We need to be out by 10am'.
- Reduce the demands when they are struggling.
- Typical ASD strategies such as repetition, routine, rewards do not work.
- Rewards don't use the same one long term but try surprise rewards as these may not work in the usual way.
- Set challenges such as 'I don't think you can do this by the time I come back!'
- Variety is often effective.
- Slow down your decisions if being out manoeuvred.
- Resist the temptation to have the last word yourself.
- Take nothing personally.
- Balance tolerance and demands: when their tolerance slips reduce the demand.
- Establish the non-negotiable such as that nobody gets hurt or to stay at home.
- Try to understand the child better, not to change them.



PARENT RESOURCES

Pathological Demand Avoidance (PDA)

- Use humour.
- Be intuitive, positive, creative and flexible. Back down when necessary.
- Use indirect praise.
- Use role play.
- Depersonalise. Try thinking out loud. "I wonder if...?"
- Make sure there are clear boundaries with things that you will not be flexible on with. Ground rules need to be as few as possible but then maintained.
- Use techniques such as passing over responsibility e.g. "I'm sorry but it's a health and safety requirement."
- Depersonalising through the use of imaginary characters, visual clarification etc.

MORE STRATEGIES TO TRY AT HOME

Allow take up time

Plant the seed of what you would like to happen, but don't expect it to happen straight away.

Give your child choices

Giving simple choices will help the day run smoothly. This gives children a sense of having some control, while ensuring that you keep the overall control i.e. "Do you want to make your bed first or bring me your washing?"

So doing the task is a given, some things do happen, they have no choice about that, but they do have the choice of how.

Use your child's interests

Using characters of interest can help depersonalise demands, as you are not personally asking them to do something. For example, if the child loves Frozen or Disney, try to find a character you can use to make requests or you could find a toy or puppet to represent the character.

Humour

If you feel the tension rising, humour is a fantastic distraction. You could try making jokes, being silly or feigning ignorance. This just takes the edge off the demand.

Use distraction

Distraction can be a handy way to temporarily press 'pause' and ease the child's anxiety. For example, when they find something quite stressful say, "Well that's fine, why don't you just come and do some jobs for me? You don't have to do your homework right now, just come and do some jobs, and you can give me a hand."



PARENT RESOURCES

Pathological Demand Avoidance (PDA)

PARENTS/CARERS WELL-BEING

Parenting/caring can be rewarding, but at times physically and emotionally draining. To enable you to support your child effectively, you need to ensure you are monitoring your own well-being. Keep a check on your personal physical and mental health and seek your own support when needed.

USEFUL PDA CONTACTS/INFO

www.autismeducationtrust.org.uk 07827283494

www.austism.org.uk/enquiry 08088004104

www.childautism.org.uk 01344882248

www.autism.org.uk

USEFUL PARENT/CARER SUPPORT

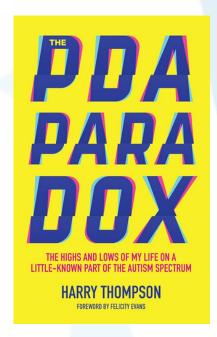
www.nhs.uk/reach4wellbeing

www.supportline.org.uk 01708765200

www.family-action.org.uk/what-we-do/children-families/send/send-info

www.earlyhelphub.co.uk 01905822666

RECOMMENDED READING





UNDERSTANDING
PATHOLOGICAL
DEMAND
AVOIDANCE
SYNDROME
IN CHILDREN
A GUIDE
FOR PARENTS,
TEACHERS
AND OTHER
PROFESSIONALS

PHIL CHRISTIE, MARGARET DUNCAN, ZARA HEALY AND RUTH FIDLER