

Demand Avoidance Vs Pathological Demand Avoidance (PDA)



Child Development Team

This booklet aims to provide an understanding of the differences between regular demand avoidant behaviours and Pathological Demand Avoidance (PDA). Strategies and resources for parents, children and young people will be explored and information on organisations that can offer further advice and support will be provided.



WON'T



OR

CAN'T

What is demand avoidance?

Regular demand avoidance

Demand avoidance is a natural human trait – avoiding demands is something we all do to different degrees and for different reasons. It involves not being able to do certain things at certain times, either for yourself or for others, and also refers to the things we do in order to avoid demands.

Demand avoidance and autism

It is common for autistic people to display demand avoidant behaviours. The autistic person may avoid demands or situations that trigger anxiety or sensory overload, disrupt routines, involve transitioning from one activity to another, and activities/events that they don't see the point of or have any interest in. They may refuse, withdraw, 'shutdown' or escape in order to avoid these things. Helpful approaches include addressing sensory issues, helping individuals adjust to new situations (for instance by using visuals or social stories), keeping to a predictable routine, giving plenty of notice about any changes and accepting that avoiding some things is perfectly acceptable.

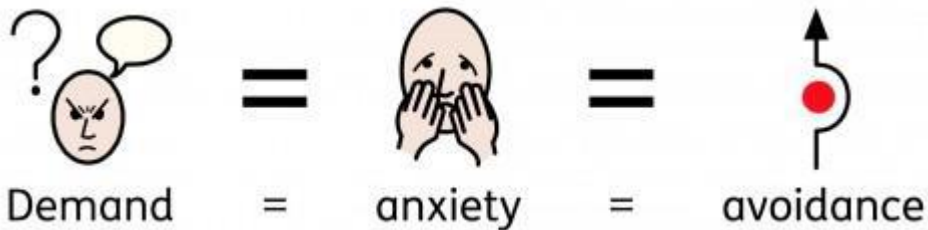
Demand avoidance and Pathological Demand Avoidance (PDA)

With PDA, these same types of demands or situations may be avoided for the same reasons. However, *pathological* demand avoidance is all-encompassing and has some unique aspects:

- Many everyday demands are avoided simply because they are demands. Some people explain that it's the expectation (from someone else or yourself) which leads to a feeling of lack of control, then anxiety increases and panic can set in
- In addition, there can be an 'irrational quality' to the avoidance – for instance, a seemingly dramatic reaction to a tiny request, or the feeling of hunger inexplicably stopping someone from being able to eat
- The avoidance can vary, depending on an individual's capacity for demands at the time, their level of anxiety, their overall health/well-being or the environment (people, places and things)
- PDA demand avoidance isn't a choice and is lifelong – it's seen in infants and remains part of the experience into old age
- With understanding, helpful approaches from others and finding coping strategies it can become more manageable.

(PDA Society)





What is Pathological Demand Avoidance (PDA)?

Pathological Demand Avoidance (PDA) was first described by Professor Elizabeth Newson in the 1980s as a pervasive developmental disorder. Today the National Autistic Society recognises PDA as part of the autism spectrum, but in some regions PDA does not yet have formal diagnostic status.

East Sussex Position Statement regarding Pathological Demand Avoidance (PDA) - July 2020

The following position statement has been co-produced between Education and Health professionals and the East Sussex Parent Carer Forum to ensure a shared understanding of Pathological Demand Avoidance (PDA) and how best to support children with this profile and their families.

Perhaps the best way of thinking about PDA is as a way of describing a range of anxiety-driven behaviours where the child or young person seeks to talk their way out of or avoid everyday seemingly reasonable requests because they trigger anxiety.

Pathological

...means that this demand avoidant behaviour is extremely debilitating for the young person.

“Actions are completely out of the control of the individual; they are not being wilful or rude. Nor can it be regarded as a power game, or being naughty. For the person concerned a request (demand) is likely to produce a level of anxiety that is beyond anything the rest of us can even begin to imagine.”

Demand

...means any demand: direct, indirect, implied or consequence. Even internal demands such as ‘I ought to’ are included.

Avoidance

...means that the individual will not be able to do what is asked of them. It is not that they do not want to; they cannot.

Tigger Pritchard (2017)

This set of behaviours may be termed Pathological Demand Avoidance and, in some areas of the country, young people may even receive a separate diagnosis of PDA.

PDA does not appear as a separate diagnostic condition in nationally and internationally recognised diagnostic manuals such as DSM-V or ICD-10. For this reason, NHS professionals in East Sussex do not make this separate diagnosis. However, for a child who has been assessed as being on the autism spectrum and presents with a PDA profile, this will be recognised and described within the child’s assessment report and diagnosis.



What might a PDA profile look like?

Children and young people with a PDA profile may use a number of strategies in response to demands, for example delay tactics, distraction, shouting, falling to the ground, saying body parts don't work, negotiating, escape, difficult or dangerous behaviour.

Behaviours that are typically seen are:

- Resistance to / avoidance of everyday demands
- Uses social strategies as part of avoidance
- Sociable, yet lacking depth of understanding
- Excessive mood swings
- Comfortable in fantasy / imaginative play
- Displays obsessive behaviour, often focused on other people

How do we support children and young people with PDA?

Children and young people with this profile do not generally respond to the traditional approaches recommended for autism. Often the children and young people respond better to a more flexible and non-confrontational set of personalised approaches. The most important thing is to gain a strong understanding of the presentation of the individual and to use approaches which are going to be most effective for them.

Schools can gain further information and support from the Communication, Learning and Autism Support Service (CLASS), and the Educational Psychology Service (EPS), both part of East Sussex County Council's ISEND service. Parents can access information and support from CLASS+.

Autism statement

We are committed to supporting all children and young people with autism. Autism is an umbrella term that describes a range of conditions, some of which you may have heard described as Asperger's syndrome, Autism Spectrum Disorder / Condition (ASD, ASC), high functioning autism, social communication disorder, pervasive development disorder or pathological demand avoidance. We recognise that each individual has a unique set of needs and strengths which we will support with a coordinated partnership approach across the voluntary and community sector, education, social care and health.

Links

Communication, Learning and Autism Support Service ([CLASS](#))

Educational Psychology Service ([EPS](#))

CLASS+ (<https://www.facebook.com/CLASSPlusEastSussex/>)

National Autistic Society (<https://www.autism.org.uk/about/what-is/pda.aspx>)

PDA society (<https://www.pdasociety.org.uk/>)

What does it feel like to have PDA?

How each child and young person experiences demand avoidance will vary across different times, ages and environments – we are all individuals. The following quotes are how some children and young people have described how living with PDA feels for them.

"I feel most anxious when I'm pressed to do something I feel I can't do, but when people around me don't understand what I mean when I say "I can't do that". I know how to do things, and I can do them sometimes, but most of the time I just can't. It starts with avoidance but if someone is insisting I'll go straight to panic. I go from being sort of OK to crashing down a hill. It's the most frustrating thing to have the functional capacity to understand what's happening but the functional ability just isn't there. It's the worst form of self-sabotage."

"It's like a great big whoosh of NO!"

"Although I'm acting angry what I'm feeling is terror, and afterwards I don't remember what I've done"

"When people speak to me in an authoritative way it makes me want to punch them really hard!"

"Demand avoidance makes it sound like I'm avoiding things on purpose, but I literally have no choice in it whatsoever. So I prefer to call it demand anxiety."

"It's like my body has 2 control centres, one is my heart and one is my brain. My heart wants to do something but my brain says no, and no matter how hard I try my brain just won't let me do it. It's like there's a train, and there is a driver at each end, both drivers are pulling in a different direction so the train can't go anywhere, it just stays still, it freezes like me"

"It's like you're gaming and you have the main controller, and then sometimes someone yanks that controller away from you and you lose control and feel panicky,"

Understanding how demand avoidance feels for your child is key in enabling you to help them develop self-help techniques and coping strategies.

"PDA is like trying to face your phobias every waking moment! For me it's like being in a malfunctioning robot. Every button I press has an opposite reaction to my intentions."

Resources describing PDA from the child perspective:
Isaac Russell: <https://youtu.be/0gCXwBh2saQ>

(Taken from the PDA Society)



Lets take a closer look at what we mean by 'demands'?

Demands come in a variety of forms.

They can be thought of as two different types: **direct demands** and **indirect demands**.



| Examples of DIRECT demands: | Examples of INDIRECT demands: |
|--|--|
| <ul style="list-style-type: none"> Instructions Rules Commands Laws Requests Expectations Timetables (including visual routines) Responding to questions | <ul style="list-style-type: none"> Feeling hungry Night and day Desires Implied demands Perceived expectations Wanting to do something but not being able to start or complete it Going out on a family day out |

Consider the various *direct* and *indirect* demands your child is exposed to on a daily basis and record them here:

| DIRECT Demands: | INDIRECT Demands: |
|-----------------|-------------------|
| | |

Now consider which demands could be removed / reduced?

Adopting an indirect style of communication

Often, by changing the language we use, we can help to reduce or disguise the demand, making it easier for the child / young person to complete tasks.

“Bet I can get my coat on before you!”

Use indirect commands to disguise demands and make them fun. Try challenges such as:

“Can you show me...”

Try to make them feel useful which also helps to maintain emotional well-being. For example:

“It would be really helpful if you could just...”

Offer limited choices to give the child a sense of control & autonomy. For example:

“Do you want a bath or shower tonight?” followed by “Would you like your bath at 6pm or 7pm tonight?”

Misread words in books

Pretend you don't know / get it wrong and ask them to teach you. For example:

Ask them to show you how to do a certain task that you want them to do

Your child may take on a role or ask you to communicate to them as a particular character in order to cope with the demand

Use role play, props and the child's interests to depersonalise demands. For example:

“Teddy has asked if we can go to the shops today?”

Avoid using these ‘demand’ words:

Need
Must / Must not
Will / Won't
Can't
It's time to
Now
By (a time/date)



Instead try non-confrontational requests:

Is it okay with you if...
How do you feel about...
Do you mind...(doing/going)
Would / Could you...
If you're happy to...
When you have finished with...could you then...

Demand Avoidance and Traditional Parenting Approaches

Sometimes praise and rewards are perceived by the demand avoidant / PDA person as another form of demand. This is why the more traditional parenting approaches such as rewards, praise and sanctions / consequences are not usually effective in PDA households.

Rewards :

Rewards can create an additional demand on top of the demand itself; they magnify the problem if something isn't achieved because not only is the 'thing' not achieved the reward isn't earned either; and they don't address the underlying difficulties or lacking skills which may have prevented achievement in the first place.

Instead try:

Surprise, 'in the moment' rewards which are given immediately (rather than waiting until the end of the activity/day/week) and rewards that are tangible (rather than stickers or collecting tokens). Finding a 'reward' that means something is key e.g. things linked to their special interest or involve time to pursue their preferred activity.

Sanctions or consequences:

Sanctions or consequences may feel unfair when behaviours are a question of "can't" not "won't", and may appear controlling when not directly related to the behaviours in question (e.g. what connection is there between not being allowed on electronics and being mean to a friend?) – they tend to lead to confrontation and escalation.

Instead try:

Natural consequences which flow from behaviours (e.g. a friend not wanting to play or not being able to watch TV if it got broken during a meltdown) enable lessons to be learned in a more realistic way. When everyone is calm, discussing ways to avoid difficult situations from arising in future is another way for natural consequences to unfold.

Praise:

Praise may be perceived as a demand to repeat or improve on previous performance, and **encouragement** can feel like a demand as it increases the sense of expectation.

Instead try:

Praising indirectly, for example, praising the results rather than the person (e.g. "what a wonderfully tidy room" rather than "well done for tidying your room") or praising your child to a third party in your child's earshot. **Focusing on the process rather than the outcome** can also be helpful (e.g. "you really persevered to get that homework done" rather than "that is an excellent piece of homework"). **When offering encouragement, providing choices and exit strategies can be effective** (e.g. "It would be great for you to go to the cinema with your friends, but don't worry if it feels too much once you're there, you can call me and I'll come and pick you up").

Parenting a PDAer: Helpful Approaches Recommended by Parents

BE FLEXIBLE!
PDA children need *flexibility* and need to be made *to feel in control*

Set **minimal (essential) boundaries**, keep routines flexible, guide rather than tell

This may require you to **consider your own triggers and beliefs** based on cultural and societal expectations

Techniques to demonstrate empathy include:
Mirroring (copy verbal / non-verbal behaviours e.g. arm position
Asking what happened ('Would you like to tell me about it..')
Listen and validate by repeating back their words
e.g. "I know you hate cleaning your room, I used to hate cleaning my room too. How about we clean it together?"

PICK YOUR BATTLES!
Ask yourself **what *really* matters** and what does not?

DEPERSONALISE RULES:
e.g. "It's a Health and Safety rule"

DEMONSTRATE EMPATHY FIRST before taking any other action. This will help the child to feel heard and support you to reconnect and de-escalate the situation

SHARE THE DEMAND
e.g. "Let's tidy your room together"

Let individuals plan their own routine

Identifying your own triggers and coping strategies will help you to remain calm

CREATE SPACE
Children with ASC / PDA can find it hard to regulate their emotions – make sure they have a safe, calming space they can go to

REMAIN CALM:
any change in your tone of voice or body language may be seen as a demand

Have an exit strategy or code word

PLAN AHEAD
anticipate what may be tricky for your child?
Identifying triggers in advance means you can plan strategies in advance

MONITOR YOUR CHILD'S STRESS LEVELS and scale back demands when you notice stress levels increasing

USE HUMOUR!
When you feel the tension rising try making a joke, funny expressions, a silly walk etc – humour is a great distraction and de-escalation tool

PDA: STAGES OF AVOIDANCE

The avoidance methods used are instinctive to the person with PDA. They are not thought through very often, at least not consciously. The type and level of avoidance that erupts will depend on factors including: the level of demand, the environment in which the demand occurs, how anxious they are already, how much demand has occurred recently, who is making the demand and the person's own personal triggers. Remember PDA demand avoidance is ANXIETY DRIVEN therefore your child's ability to manage demands will depend on how full their anxiety bucket is at the time.

ANXIETY IS LIKE A BUCKET OF WATER.

IF WE KEEP ADDING STRESSORS TO THE BUCKET, OVER TIME IT FILLS UP.



UNTIL, ONE DAY, IT OVERFLOWS.

Stage 1: Light Avoidance

- Distraction
- Procrastination
- Negotiation
- Excuses
- Masking

Stage 2: Strong Avoidance

- Retreating into role play / fantasy
- Outrageous social behaviour
- Incapacitating themselves
- Ridiculous excuses
- Outright refusal

Stage 3: Melt/Shut down

- Physical / emotional harm of self or others
- Destruction of property
- Extreme exhaustion
- Uncontrollable crying
- Depression / anxiety

Sometimes the person can start at level 1 and build. Sometimes you can support them to bring themselves down before getting to level 3. Sometimes they will go straight to level 3 with (what seems like) no warning.

Avoidance Strategies

Individuals with PDA will use a wide range of avoidance strategies:

How demands are avoided:

Manipulating social situations to remain in control

Refusal – I can't / I won't

Making excuses- My legs don't work!

Distraction – Oh look there's a..

Delaying

Suggesting alternatives

Withdrawing into fantasy

Melt down or shut down

Do you recognise any of these? Consider what avoidance strategies your child uses.

Use this space to identify your child's avoidance strategies:

Now consider what stage of avoidance your child is experiencing when displaying these avoidance strategies. What strategies could you use to help de-escalate the situation and support your child to feel safer ? (safety + trust = calm)

Managing Meltdowns

Meltdowns are a full-body reaction to being overwhelmed. They are more extreme than tantrums, and the child / young person is not in control of them.

Managing meltdowns is more complicated than taming tantrums. Knowing the triggers can help you avoid or de-escalate a meltdown but even if you can't stop a meltdown, there are ways you can respond to help your child regain control.



Before the Meltdown

1. Get to know your child's triggers.

These will not be the same for every child, and your child may be reacting to something that is not obvious to us. For some children, it might be emotional or sensory overload. For others, it might be demands, unexpected changes, or pain and fear. You may notice that your child gets anxious before school or falls apart at the end of the day. Or maybe meltdowns happen close to mealtimes or bedtime; in that case, hunger or fatigue may be triggers. Or you may notice that there are certain places where they happen, like noisy or crowded environments.

Knowing your child's triggers can make it easier to avoid and reduce meltdowns.

2. Notice when it is escalating.

If you catch the signs early enough, you might be able to help your child calm down before a full-blown meltdown occurs. Common warning signs are:

- Trouble thinking clearly, making decisions, or responding to questions
- Repeating thoughts or questions over and over
- Refusing to follow directions or co-operate
- Trying to shut out noises, sights, and other sensory things, or trying to run away or hide
- Moving restlessly, like fidgeting or pacing
- Complaining of physical issues like dizziness or heart pounding



3. Try to distract from the trigger.

For some children, the escalation phase can be interrupted. It might help to distract your child with a different task or activity or some children may respond to the use of humour as a distraction such as a silly dance.



4. Be patient.

Your instinct may be to try to stop an escalation quickly. But talking fast and loud often makes it worse. Give your child more space and more time to process what you are saying. Use short, concrete sentences that take away your child's need to make decisions.



During the Meltdown

1. Do a safety assessment.

When your child is screaming and throwing things, it may feel like an emergency. But that doesn't mean it is. The question to consider: is anyone hurt or going to get hurt?

2. Be reassuring.

It takes trial and error to know if your child wants physical distance or a firm hug or touch. Keeping your voice and body language calm is helpful in either case. Make sure your child knows you are there and that you understand that this may feel scary and out of control.

3. Give some space.

If you are out in public, try to help your child move to a quieter place. If you are at home, see if you can get your child to go to a spot that's calm. If it's not possible to move your child, ask other people to leave the area to give you both some space.



4. Tone it down.

Turn down lights, keep things quiet, and try not to crowd your child. If you are at home and your child isn't able or willing to move, try standing off to the side (standing in the doorway can make a child feel blocked in.)



5. Consider your post-meltdown plan.

Start thinking about how to reengage with your child when the meltdown is over, rather than do something that starts it up again. You may need to abandon your shopping trip. If the meltdown was triggered by an emotional conversation, you may need to back away from that topic. You can find a new way to approach it the next time you talk about it.



After the Meltdown

1. Take time to recover.

When calming down, your child might feel embarrassed or guilty. You'll probably see physical exhaustion, too. Give your child some time to recover.

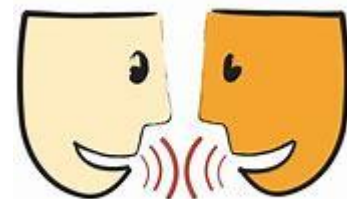


2. Find the right time to talk.

You can help your child make sense of what happened. Right after a meltdown may not be the best time, though. When you are both calm, here are some ways to approach it:

Give your child a heads-up. Give advance notice that you're going to talk and be reassuring that your child's not in trouble.

Be brief. Talking about a meltdown can make children feel bad and defensive. Say what you need to say, but try to avoid saying the same thing over and over.



Make sure your child understands. Ask your child to tell you what you talked about and answer any questions. If you've decided on an action plan, see if your child can repeat it for you.

Managing meltdowns takes practice. Learning to recognise the signs and teaching your child coping skills can help you both find better ways to respond in the future.

Remember:

Tantrums and meltdowns can look similar but aren't the same thing; they need to be responded to differently.

Knowing why your child has tantrums or meltdowns can help you avoid them.

Assigning a "calm space" can help with both tantrums and meltdowns.

Learning your child's triggers can help keep a meltdown from escalating.

Adapting Your Parenting Style: Top Tips

Parenting a PDAer requires us to completely rethink our parenting style. This can be extremely challenging. Not only do we need to be honest about our own beliefs and values (based upon how we were parented ourselves) but also requires us to go against the more traditional and 'expected' parenting approach (based on societal expectations of what is considered 'good parenting'). It is common for relatives and friends to find it difficult to understand and accept this different style of parenting and can therefore leave you feeling isolated. We recommend reaching out to other PDA families through attending workshops and support groups either face to face or via social media and obtaining support and guidance through local support services.

You will find a list of support services and organisations at the end of this booklet.

Key questions to ask yourself:

- What are you trying to achieve?
- What is your child learning?
- What is the overall impact of YOUR actions?
- What REALLY matters?



Identify the desired outcome (demand) then think *how can we achieve the outcome while helping the child feel safe and 'in-control'?*

Think SUPPORT NEED rather than discipline for challenging behaviour

Remember, your child's demand avoidance is anxiety led therefore tolerance levels will vary depending on how full their anxiety bucket is. Your child may be able to manage a task one day but not the next...remain flexible and let go of what does not matter.



Resources:

Websites

- www.pdasociety.org.uk
- www.autism.org.uk
- www.positiveautismsupportandtraining.co.uk
- www.thepdaresource.com
- www.sallycatpda.co.uk

Books

- Me and My PDA – A Guide To Pathological Demand Avoidance (Dr Glòria Dura-Vilà and Tamar Levi)
- The PDA Paradox (Harry Thompson)
- Pathological Demand Avoidance Syndrome – My Daughter is not Naughty (Jane Sherwin)
- Can I tell you About Pathological Demand Avoidance Syndrome? A Guide for friends, family and professionals (Ruth Fidler and Phil Christie)
- Super Shamlal – Living and Learning with Pathological Demand Avoidance (K. I. Al Ghani)
- Sally Cat’s Pathological Demand Avoidance Explained (Sally Cat)
- Understand Me - An inspiring journey of a boy with PDA (Spencer Stott)
- Life on an Alien Planet: A PDA boy and his journey through the education system (Katie Stott)
- Do You Know Me? (Co-written by twelve-year-old autistic blogger Libby Scott and Rebecca Westcott)
- Pretty Darn Awesome L(auren O'Grady)
- Saturdays at Noon (Rachel Marks)
- Me and My PDA (Glòria Durà-Vilà and Tamar Levi)

Local Support Services, Resources and Workshops

- CLASS+: Contact CLASS@eastsussex.gov.uk, message them on their [Facebook page](#) or call 01273 336887 for more information
- Child Therapy Service – a therapeutic toolbox: <http://www.childtherapyservice.org.uk/>

As PDA is an anxiety based condition we recommend you also read our Managing Anxiety booklet. You can request a copy of this by emailing the Child Development Nurse Team:

esht.cdnt@nhs.net