

Pathological Demand Avoidance Profile

What is it? What does it really mean?



Introduction and my background

- ∞ I am the class teacher for our class of pupils with demand avoidant profiles
- ∞ I have specialised within demand avoidance and Pathological Demand Avoidance, advancing my knowledge through qualification study, research and experience in this field
- ∞ My experience of working with children with PDA spans multiple settings
- ∞ My own son has PDA

The purpose of this webinar is to support understanding of PDA and dispel the myth that it is *just bad parenting*.

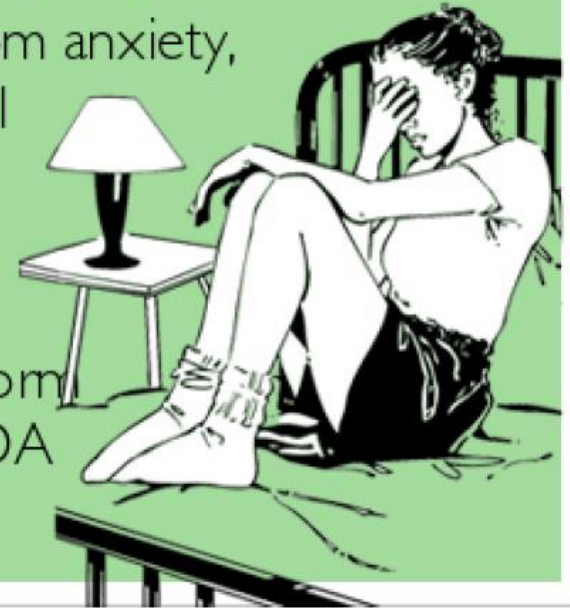
Pathological Demand Avoidance
is a complex, challenging and
misunderstood condition that is often
ignored or not
even
recognized by
many

professionals
somee cards
user card



Behind the behaviour is a
child suffering from anxiety,
depression, social
isolation and
low self esteem
caused by a
misunderstood form
of ASD called PDA

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user card



What do we mean by PDA?

- ∞ **Pathological:** *“extreme in a way that is not normal or that shows an illness or mental problem. Obsessive or compulsive”*
- ∞ **Demand:** *“a forceful statement in which you say that something must be done or given to you”*
“a strong need for something”
- ∞ **Avoidance:** *“the act of avoiding something”*
- ∞ **PDA is** *“an anxiety driven need to avoid demands and to remain in control at all times” (Jane Sherwin)*

- ∞ Do we not all do this sometimes?
 - ∞ So why are we all not diagnosed as PDA?
- ∞ PDA is anxiety driven by people who have very low self esteem
- ∞ How is PDA and DA different then?



Lets compare

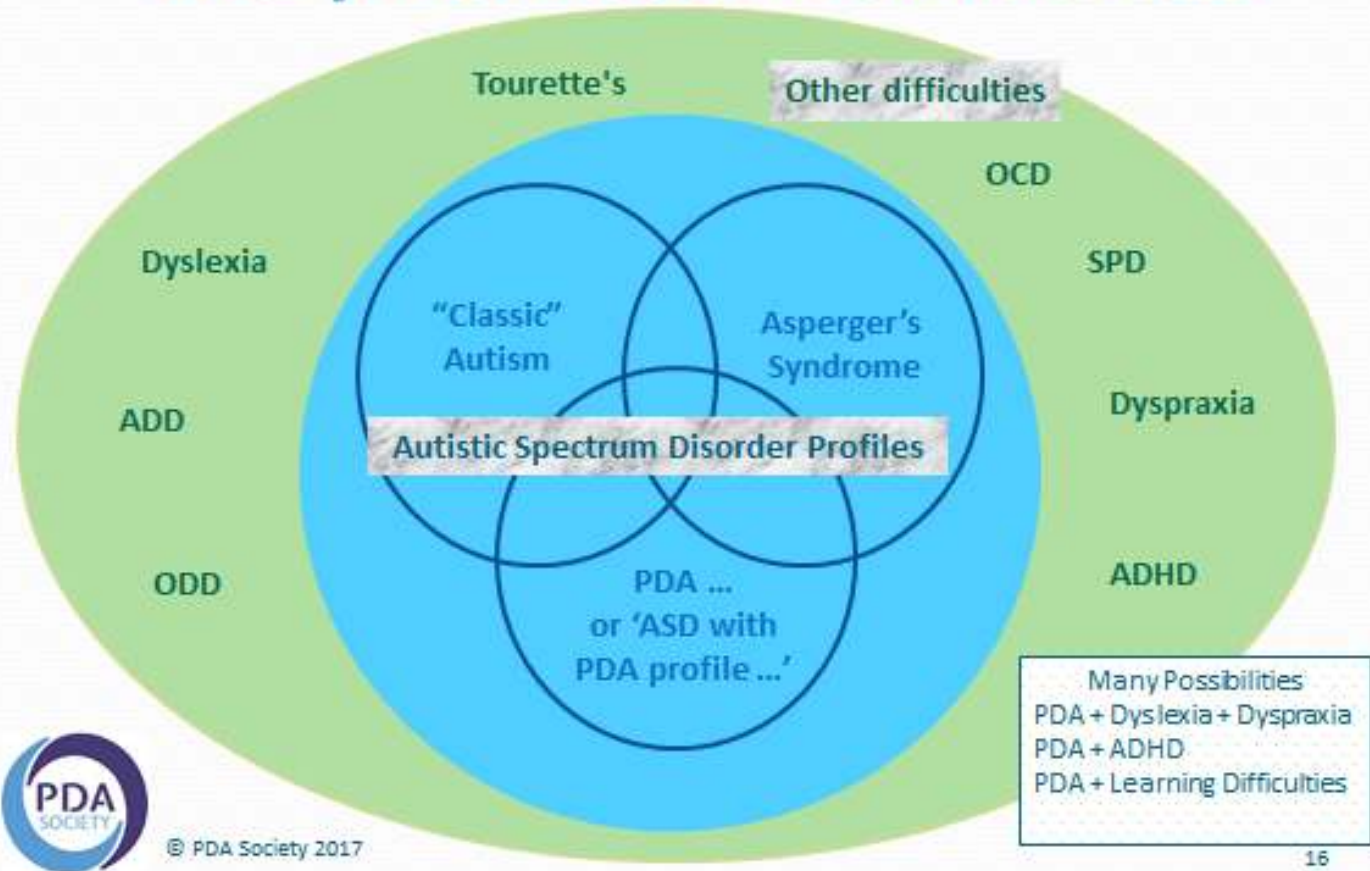
Pathological Demand Avoidance

- ∞ Resisting and avoiding ordinary demands of life
- ∞ Large reactions to seemingly small triggers
- ∞ Will NOT accept any sort of reward – these create anxiety

Demand Avoidance

- ∞ Resists demands or situations which may trigger anxiety or sensory issues
- ∞ Are more open to reasoning
- ∞ Will accept a “reward” for compliance

Every individual is different....



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Demand

=



anxiety

=



avoidance



Where does PDA come from?

- ∞ PDA is part of the autistic spectrum. Not all people with autism have PDA but everyone with PDA has autism. This is also the main difference with Oppositional defiant disorder (ODD) as you do not need to have a diagnosis of autism to have ODD.
- ∞ PDA is extremely anxiety driven. Reduce demand and you reduce anxiety
- ∞ PDA falls within the autism spectrum though many typical signs of autism will not be seen
- ∞ Behind a PDA person is someone who is anxiety driven and likely to be suffering from depression, isolation and low self esteem due to PDA often not being recognised.

Autism

- ∞ Compulsive adherence to routines – find spontaneity hard to cope with
- ∞ Can prefer their own company at time
- ∞ May respond well to motivators and rewards
- ∞ Avoid eye contact
- ∞ Can be manipulated (vulnerable)
- ∞ More likely to experience a wider range of emotions and understand them
- ∞ Experiences empathy and imagination in a different way to NT children

PDA

- ∞ Resist demands obsessively
- ∞ Socially manipulative (control games)
- ∞ Normal eye contact
- ∞ Show role play
- ∞ Are more comfortable socialising in groups
- ∞ Not understand social hierarchy
- ∞ Excessive reactions very quickly (green to red zones)
- ∞ May not respond well to rewards / rigid behaviour management plans
- ∞ May communicate differently to typical Autism
- ∞ 50/50 prevalence rate across male/female

Let's explore demands



Surely we can "solve it"
by just not giving a direct demand?

If only! There are 4 types of demand

Direct

- ∞ put your pencil case away please
- ∞ Say "please"
- ∞ Do your homework



Indirect

- ∞ Please can we have a clear desk?
- ∞ It's time for you to....
- ∞ We need to.....



Silent demand

- ∞ Answering questions
- ∞ Following a timetable
- ∞ following rules, social etiquettes



Self imposed demands

- ∞ following personal hygiene
- ∞ leaving the house
- ∞ Speaking
- ∞ Eating or taking medication



The demands need to be reduced as much as possible and the PDA person needs to feel safe with other people and the environment they are in to help reduce their anxiety. Only then can they move forward.



Are there that many demands?

∞ I would like you to think about how you perceive your morning routine.

Do you get up and follow a routine?

If your routine is interrupted how does this affect your morning?

Do you feel anything other than I need to get ready and go to work?

Now lets think about how the PDA child approaches their morning


Morning routine demands

- ∞ An alarm clock or parent waking them up
- ∞ Expected to get up
- ∞ Expected to eat breakfast
- ∞ Expected to wash, brush teeth, brush hair
- ∞ Expected to get dressed
- ∞ Expected to remember their bags and lunch
- ∞ Expected to join in conversation
- ∞ Expected to get in a taxi
- ∞ Expected to leave the house



All of these are demands

- ∞ Everyone has their own routine and different things will be seen differently by each child
- ∞ Some will struggle to walk into the class
- ∞ Some will struggle to follow a heavily structured timetable
- ∞ Some will struggle with other childrens' quirks
- ∞ Some will struggle with their teacher and TA's



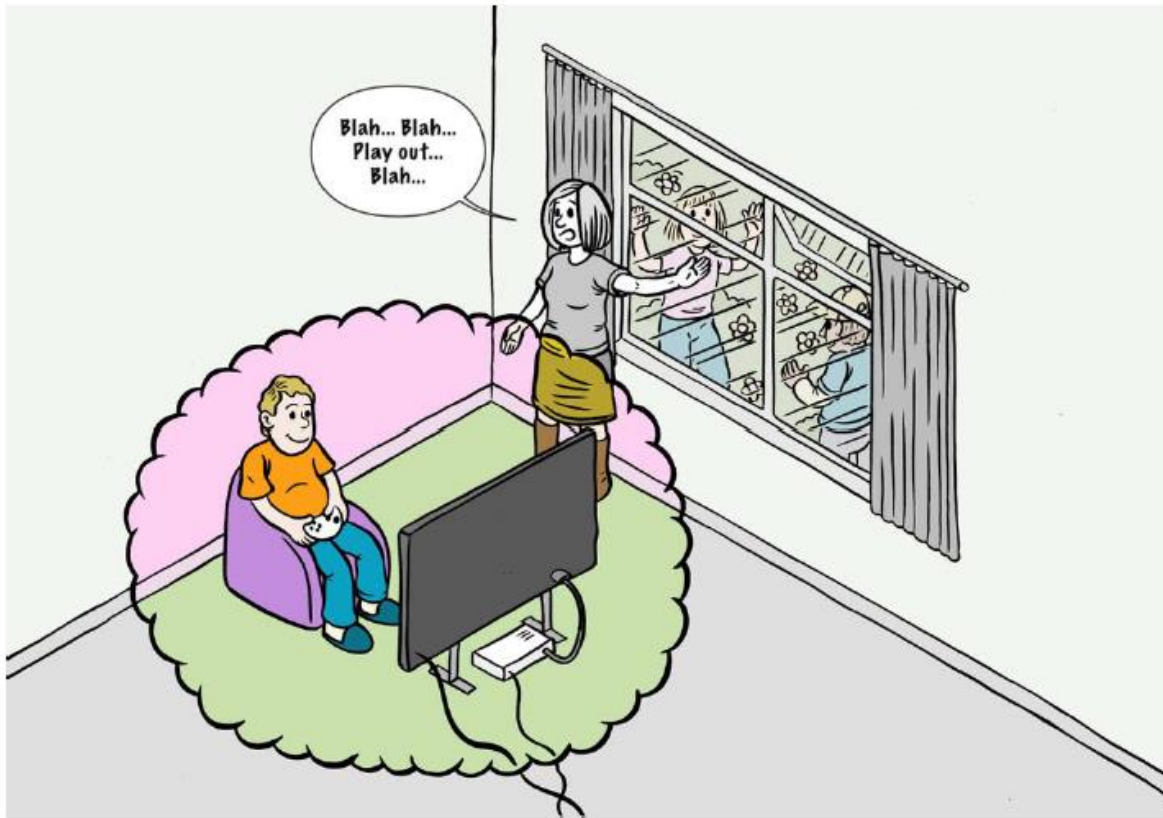
How may they react?

- ∞ Everyone reacts differently though the one similarity is the extreme of the reaction.
- ∞ Remembering that a PDA child's reaction is based on anxiety through losing control have a think about what behaviours may be displayed.

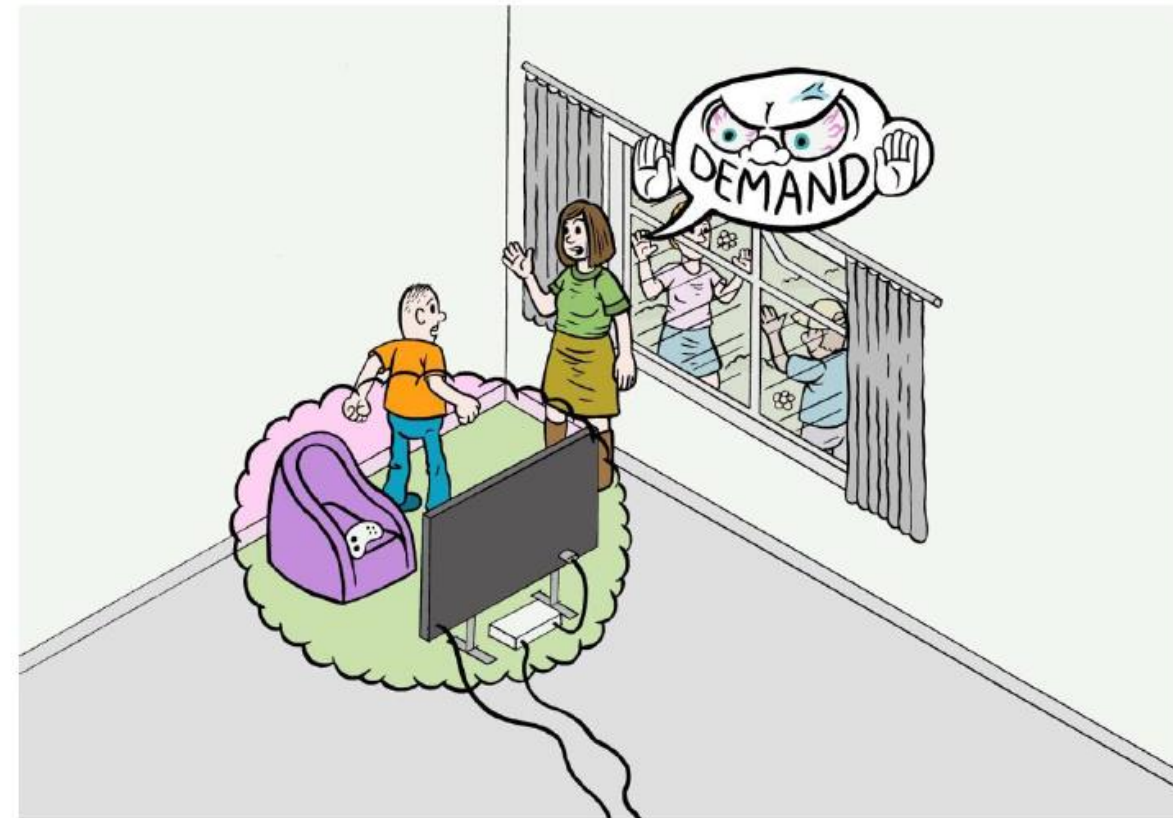
Behaviour	Reason
Surface Sociability	Need to fit in
Hyper-sensitivity to people	Hyper vigilance/anxiety
Role playing	Conforming / avoiding demands

Different types of Demand Avoidance

Autistic Inertia



Demand avoidance of the PDA kind



8 WAYS A CHILD'S ANXIETY SHOWS UP AS SOMETHING ELSE

1. Anger

The perception of danger, stress or opposition is enough to trigger the fight or flight response leaving your child angry and without a way to communicate why.



2. Difficulty Sleeping

In children, having difficulty falling asleep or staying asleep is one of the hallmark characteristics of anxiety.



3. Defiance

Unable to communicate what is really going on, it is easy to interpret the child's defiance as a lack of discipline instead of an attempt to control a situation where they feel anxious and helpless.



8. Overplanning

Overplanning and defiance go hand in hand in their root cause. Where anxiety can cause some children to try to take back control through defiant behavior, it can cause others to overplan for situations where planning is minimal or unnecessary.



4. Chandeliering

Chandeliering is when a seemingly calm person suddenly flies off the handle for no reason. They have pushed hurt and anxiety so deep for so long that a seemingly innocent comment or event suddenly sends them straight through the chandelier.



5. Lack of Focus

Children with anxiety are often so caught up in their own thoughts that they do not pay attention to what is going on around them.

FOCUS

6. Avoidance

Children who are trying to avoid a particular person, place or task often end up experiencing more of whatever it is they are avoiding.



7. Negativity

People with anxiety tend to experience negative thoughts at a much greater intensity than positive ones.

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.





Reactions to scenarios


1. Trying to come into class but the teacher is not there
2. Completing their maths but they become stuck on a question
3. Another child is behaving in a different way to normal
4. They have been asked to try something new
5. They are going to a new place like a play barn or arcade that they would normally enjoy



1. Trying to come into class but the teacher is not there

- ∞ Refusal to enter the room
- ∞ Retreating to another room
- ∞ Refusal to interact with friends or safe staff
- ∞ Swearing
- ∞ Violent reactions through throwing things
- ∞ “Masking” until the teacher returns and then the teacher will be treated to any of the above

UNDERLYING REASON: All of these are due to the child losing the security they normally have within the class so anxiety is extreme




2. Completing their maths but they become stuck on a question

- ∞ Refusal to complete any more work that day
- ∞ Flipping the table/chairs
- ∞ Shouting at staff
- ∞ Blaming the question, the question must be wrong!
- ∞ Removing themselves from the class
- ∞ Refusing to even look at that specific topic again

UNDERLYING REASON: This is due to the low self esteem so struggling tells them that they are “stupid” and reaffirms that they are no good.

This also heightens their anxiety



3. Another child is behaving
in an unpredictable or different way to usual

- ∞ Remove themselves from normal friendship group
- ∞ May copy this new behaviour
- ∞ Verbally aggressive towards their safe person
- ∞ Physically aggressive towards a safe person

UNDERLYING REASON: They may remove themselves due to not understanding this new display of behaviour

UNDERLYING REASON: They may copy it as they do not know how to disassociate themselves when they are meant to be friends

UNDERLYING REASON: The attack on a safe person will again be due to anxiety so they are displaying that they are scared



4. They have been asked to try something new

- ∞ They will already know how to do it


- ∞ Its useless so they wont bother

- ∞ They will develop a headache/sore leg etc

- ∞ Deliberately do it wrong just to prove they could not do it or that they didn't care

- ∞ Many other avoidance tactics

UNDERLYING REASON: All are to reduce anxiety, saving face just in case they cannot do it.



5. They are going to a new place
like a play barn or arcade that they would normally enjoy

- ∞ Refusal to get ready
- ∞ Cause an argument where they think you will then cancel the trip
- ∞ Refusal to take part
- ∞ Develop pains/aches
- ∞ Remember they had something really important to do

UNDERLYING REASON: All brought on by anxiety over a new place, different people, not knowing where toilets are, not knowing what behaviours are expected,

Perspectives from those with PDA

"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."

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

"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."

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

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

"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,"

"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."



Perspectives from those with PDA

A student from TCS

- ∞ “I just *have* to be in control, that's the only way I can feel, kind of, *right*.”
- ∞ “It sometimes feels like there’s an argument between two sides of my brain and body, that makes me feel stressed.”
- ∞ “My PDA brain feels more important - it’s like a burglar alarm that goes off when someone tries to be in charge, or control me, or boss me around.”
- ∞ “When I hear a command, my brain goes into ALERT mode.”
- ∞ “I try to block out the voice of anyone who’s telling me what to do, but if that doesn't work and I'm already feeling stressed I sometimes can't help lashing out. The disadvantage is, I can't always block out someone's voice, because I can hear everything, so it's hard to block things out.”
- ∞ “If someone is telling me how to do something, it just sounds too nagging, and I feel like kicking them.”
- ∞ “Instructions are really bossy. When I saw the instructions for how to build it [a toy robot], they were too bossy, so I gave it to Dad to do.”

Perspective of a parent



PDA and Family life

PDA and Family life

Things it's important to know

- A child with PDA is in a **constant state of anxiety and hypervigilance** and has a very sensitive threat response system.
- They have an extremely strong anxiety-based need for **autonomy** and any threat to that feels like an attack.
- **Demands** are many, varied and cumulative, and include many things we don't think of as demands.
- Children with PDA tend to be very good at **masking** their difficulties.
- Someone with PDA sees everyone as **equal**; there is no understanding of authority and social hierarchies.
- Basic needs of a child with PDA include: **freedom/Autonomy; control; equality in every relationship**

PDA and family life

Making it work for us

- A relationship of **trust**.
 - “The opposite of anxiety is trust.”
- Demand avoidance is **can't not won't**.
 - Being controlling and avoiding demands are protective instincts, trying to **preserve autonomy** in order to feel safe.
- A totally **different mindset** and a different way of relating to each other.
- Ensuring *everyone's needs* are met.

PDA and family life

Making it work for us

- **Low arousal and low demand** parenting:
 - Doesn't mean no boundaries and no demands!
 - Pick your battles: what are our priorities? does this *really* matter?
 - Keep rules to the minimum necessary and agree the, together.
 - Coping budget.
 - Negotiation, collaboration, choices, compromise where possible, and giving valid reasons.
 - As much autonomy as possible.
 - Present demands creatively and carefully.
 - Child's own priorities: intrinsic motivation; what's in it for them?
- **Flexibility!**
- **Experience and natural consequences**

Some advice from parents of PDA'ers



How can we help?



Over riding theme is anxiety!

So strategies need to focus on this



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.



Friendly classroom structure

- ∞ Minimal visuals
- ∞ Loose schedule on the board with elements for control integrated
- ∞ Work set-out to enable a compromise on how many questions/which questions they can do
- ∞ They have a say in their seating (this is true of all of our classes)
- ∞ Clubs at lunchtime in Tajiri class if they want
- ∞ Rewards time on Friday is Tajiri club except for those who choose a differing activity e.g. Dungeons and Dragons
- ∞ Independent work is to their own level to ensure success each time, new academic progress is made through discussions and questioning before application to written devices
- ∞ Appearance of freedom – we allow them to take control of their own education within our construction.

Why is it different?

- ∞ Visuals are a demand which are therefore Anxiety inducing
- ∞ Timetable is a heavily structured demand. Schedule allows them to work when they are ready within our requirement of gaining an education.
- ∞ If they can show they can do something then they will show you a couple of times only if you are lucky before it is pointless in their minds
- ∞ Having a say with seating reduces anxiety and gives them control
- ∞ Rewards are a demand of expected behaviour. Remove this altogether and they have a relaxed time in a safe space with usual friends
- ∞ Work with permanence needs to ensure success each time to help boost self worth until they are able to manage more challenge.
- ∞ Allowing them freedom of control reduces anxiety so more open to suggestions



How you can help supporting adults

- ∞ Sometimes the strategy is planned ignoring – this is to allow the child time to have reduced demands, sensory input and to manage their inner thoughts.
- ∞ Ask if they would like any help and if so what
- ∞ Do not have dialogues about the behavioural communication of the child in front of them, this heightens them further when in a hyper vigilant state.
 - ∞ In school, please do have open dialogues outside of the event in order to increase knowledge and offer support and ideas
 - ∞ In public this might not be possible, but a supportive gesture or cue so they can let you know may help more.
- ∞ Understand that all children are different and Teach your child to understand and celebrate differences – We all have a role to play in our world and all our contributions are unique
- ∞ Be supportive



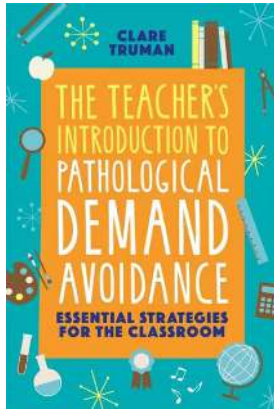
How can you help the child

- ∞ Stay calm, don't match arousal levels.
- ∞ Listen to what they are saying and really listen
- ∞ Be ready to compromise or even give in
- ∞ Sometimes just sit in silence. Anything you say may delay the ability to regulate and input could prolong or further heighten them
- ∞ Once they are regulated, move on with unconditional positive regard, until they are ready to revisit it
- ∞ Be consistent, consistently.
- ∞ Always start every day with a smile.



Moving forward

- ∞ The PDA child does not view the future in the same way as neurotypical.
- ∞ Tabletop scenario
- ∞ Ultimate goal?



The teachers guide to pathological demands in the classroom by Clare Truman

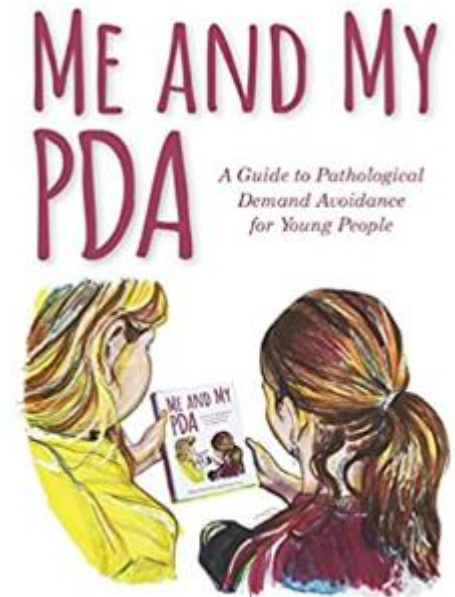


My daughter is not naughty by Jane Alison

Suggested reads:



PDA society



Glòria Durà-Vilà and Tamar Levi

Me and my PDA by Gloria Dura-vila
(for younger audience 10+)

Questions?

