



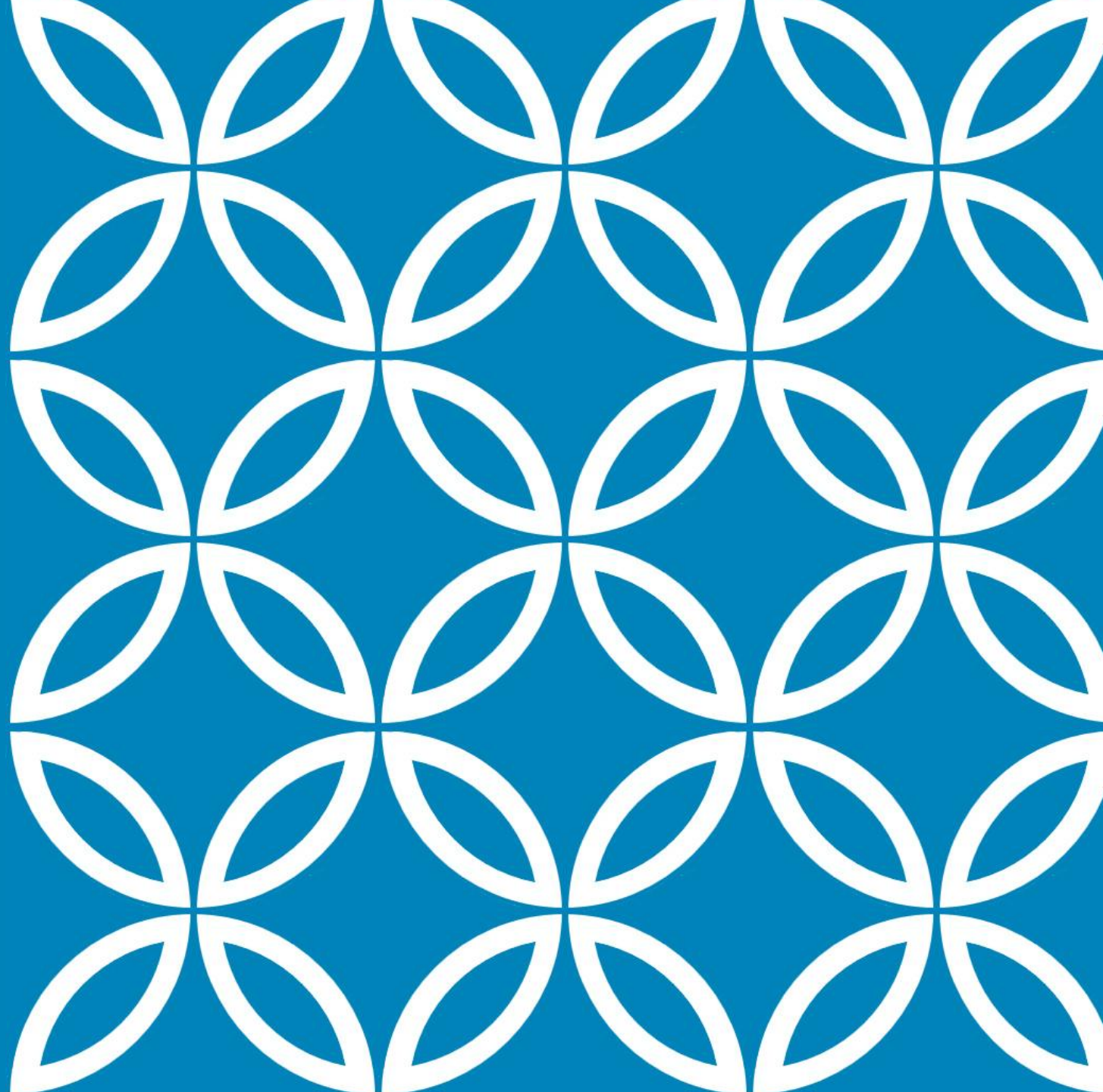
UNDERSTANDING AND SUPPORTING PDA PRESENTATIONS IN AUTISTIC CHILDREN

Tamsin Cox
Principal Educational
Psychologist

WORKSHOP OBJECTIVES

1. Explore ideas and thinking around Demand Avoidance
2. Explore the current understanding of PDA (Pathological Demand Avoidance) and PDA Profiles in the context of autism
3. Think about the challenges for a child with a PDA profile of autism – what is it really like to experience a PDA driver?
4. Explore strategies and support for a child with a PDA profile of autism
5. Remind ourselves how important it is to care for ourselves if we are supporting a child with a PDA presentation / driver

PART 1: WHAT IS THE
CURRENT
UNDERSTANDING OF
PDA AND WHAT DOES
THIS MEAN IN THE
CONTEXT OF AUTISM?





ACTIVITY 1

1. WHAT DOES PDA MEAN TO YOU?
 2. HOW DOES THIS DIFFER FROM YOUR UNDERSTANDING OF DEMAND AVOIDANCE?
 3. WHAT EXPERIENCE DO YOU HAVE OF PDA?
-

WHAT IS DEMAND AVOIDANCE?

'Demand avoidance' involves not being able to do certain things at certain times, either for yourself or others, and also refers to the things we do in order to avoid demands.

It is a **natural human trait** – avoiding demands is something we all do to different degrees for different reasons.

It is **common** for all children and young people to display demand avoidant behaviours. However, we understand that children with autism experience **much higher and more intense levels of anxiety alongside sensory/emotional overwhelm.**

It is therefore more common for them to **avoid situations** that trigger anxiety or sensory overload, disrupts routines, involves transitioning to one activity to another, and activities/events that they do not see the point of or have no interest in.

They may **refuse**, '**shut down**' or '**meltdown**', or **escape** in order to avoid these things. (Note: links to fight, flight or freeze)



What are some of the things we might all decide to / try to avoid?

WHAT IS A DEMAND?

Direct questions and instructions

Indirect demands

Implied demands

Societal expectations

Internal demands

Individual interests





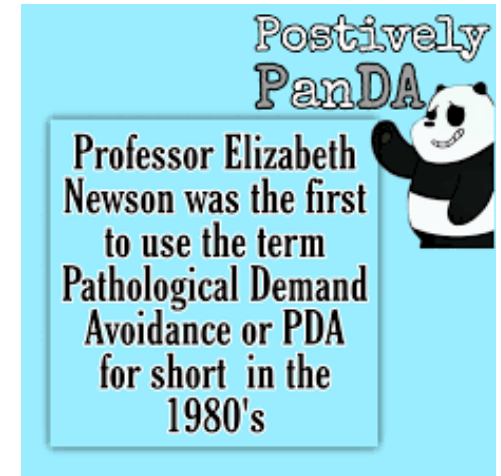
ACTIVITY 2: DEMANDS

TALK TO THE PERSON NEXT TO YOU
WHAT DO YOU THINK ARE THE DEMANDS
THAT ARE STRESSFUL FOR YOUR CHILD?

THIS COULD RELATE TO CHANGE,
TRANSITION, SOCIAL SITUATIONS, SENSORY
PRESSURES.....



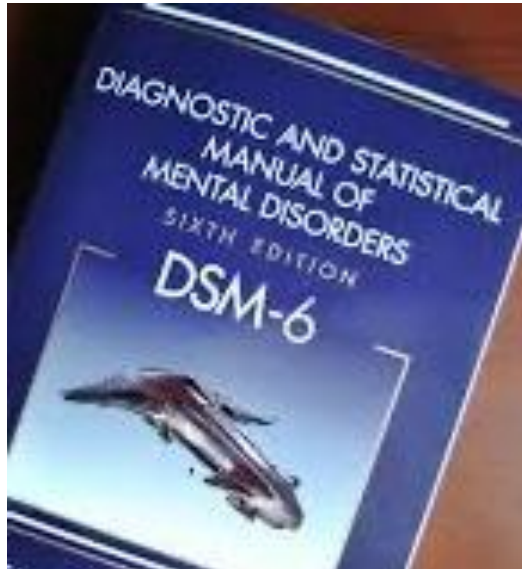
WHERE DID THE TERM PDA COME FROM?



The term PDA was developed by British psychologist Elisabeth Newson in the 1980s and first used in a published research paper by Newson in 2003.

PDA was used to describe a group of children who did not fit into the stereotypical (expected/usual) presentation of autism recognised at that time, but who shared certain characteristics with each other.

RECOGNITION OF PDA



PDA (Pathological Demand Avoidance) is not **clinically** recognised.

This means it is not included in the International Classification of Diseases (ICD) nor Diagnostic and Statistical Manual of Mental Disorders (DSM- 5).

This means you cannot receive a standalone diagnosis of PDA.

Demand avoidance, including the use of social strategies to avoid demands is widely acknowledged as a characteristic reported by and observed in some people. However, no research has found strong evidence for the group of traits proposed for PDA or tested the validity of Elisabeth Newson's theory in clinical practice.

The National Institute for Health and Care Excellence (NICE) guidelines mention PDA as a ***feature of autism***.

PDA has been conceptualised through ***lived experience / clinical practice*** rather than academic research.

IF IT ISN'T A
DIAGNOSIS -
HOW MIGHT
PDA
PRESENTATIONS
BE DESCRIBED?

Although it is not possible to receive a diagnosis of PDA, some people have a diagnosis of autism with a 'demand avoidant profile' or a 'PDA profile' noted, and others self-identify with the PDA label.

'**PDAer**' is how some people in the autistic community prefer to be referred to.

Some however strongly object to the use of the word '**pathological**' in the term 'PDA'.

They suggest '**Persistent Drive for Autonomy**' as an alternative which highlights the anxiety driver behind the presentation.

Others think use of the word 'pathological' is appropriate because they find these characteristics '**all-consuming**' on a daily basis.

DEBATE ABOUT PDA



PDA is contested within the *autism community*. It is argued that...

The PDA label represents unnecessary pathologizing (medically diagnosing) of differences in autistic people when:

- **Trying to gain autonomy (control over their lives)**
- **Adopting coping mechanisms or attempting to reduce anxiety associated with social norms or asserting self- agency (their desire to make their own decisions)**
- **Persistent Drive for Autonomy**

However, there is also counter criticism from people who identify with PDA and feel their experiences are not being recognised.

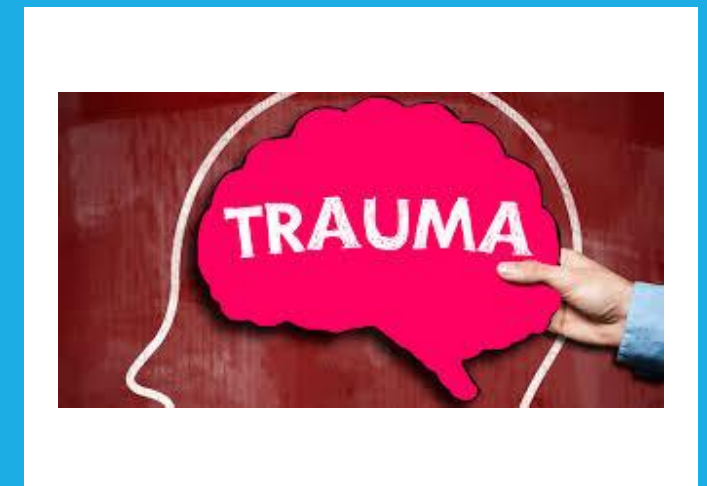
National Autistic Society (NAS) were previously criticised for engaging with PDA beyond the evidence. They have reviewed their content and approach to be in line with the current evidence.

WHAT ELSE COULD IT BE?

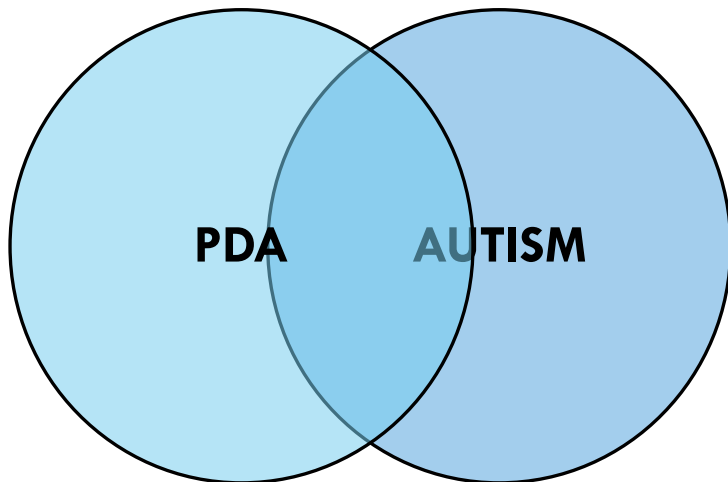
PDA is recognised as a profile of autism, so can a child have a “PDA” presentation without a diagnosis/evidence of autism?

Consider, could the behaviour be a result of:

- Sensory impairments (e.g. hearing/vision)
- Other medical conditions/issues (e.g. epilepsy)
- Environmental factors
- Excessive fear/anxiety
- Other learning and/or language difficulties
- Developmental and/or Complex Trauma
- Attachment/Relational Difficulties



WHAT IS PDA AND HOW DOES THIS RELATE TO AUTISM?



The existence of PDA and a demand avoidant profile is often disputed amongst professionals, particularly whether it is a continuum of Autism or a separate condition.

PDA is now widely considered to be part of the Autism spectrum, or one of the Autism Spectrum conditions and is therefore now often described as a profile within the context of an individual's presentation of autism.

'X has autism with a PDA profile'

Individuals with a PDA profile therefore experience differences in social aspects of interaction and communication, together with some repetitive patterns of behaviour.

Children and young people with a PDA profile often seem to have better social understanding than others on the spectrum, which means that some of their difficulties may be less obvious at first. They are also able to use social strategies in attempts to avoid demands in a way that can be described as **socially 'strategic'**.

Whilst our understanding of what it means to be autistic is increasing, the full breadth and complexity of this continues to evolve.

<https://www.pdasociety.org.uk/resources/whats-needed-better-understanding-of-pda/>

AUTISM, ANXIETY AND PDA

PDA presentations are best understood as an **anxiety-driven** need to be in control and to avoid other peoples demands and expectations.

What is known is that a high proportion of people with autism experience varying extremes of anxiety which is influenced by their internal and external environments. It is understood that anxiety is also experienced differently for many autistic people.

Even the simplest of demands by other people can **elicit a fight, flight, or freeze response** for individuals described as having a PDA profile.



AUTISM AND ANXIETY

Children with autism experience **higher levels of anxiety**, experience it **more intensely** and over a **longer period of time** than non-autistic CYP:

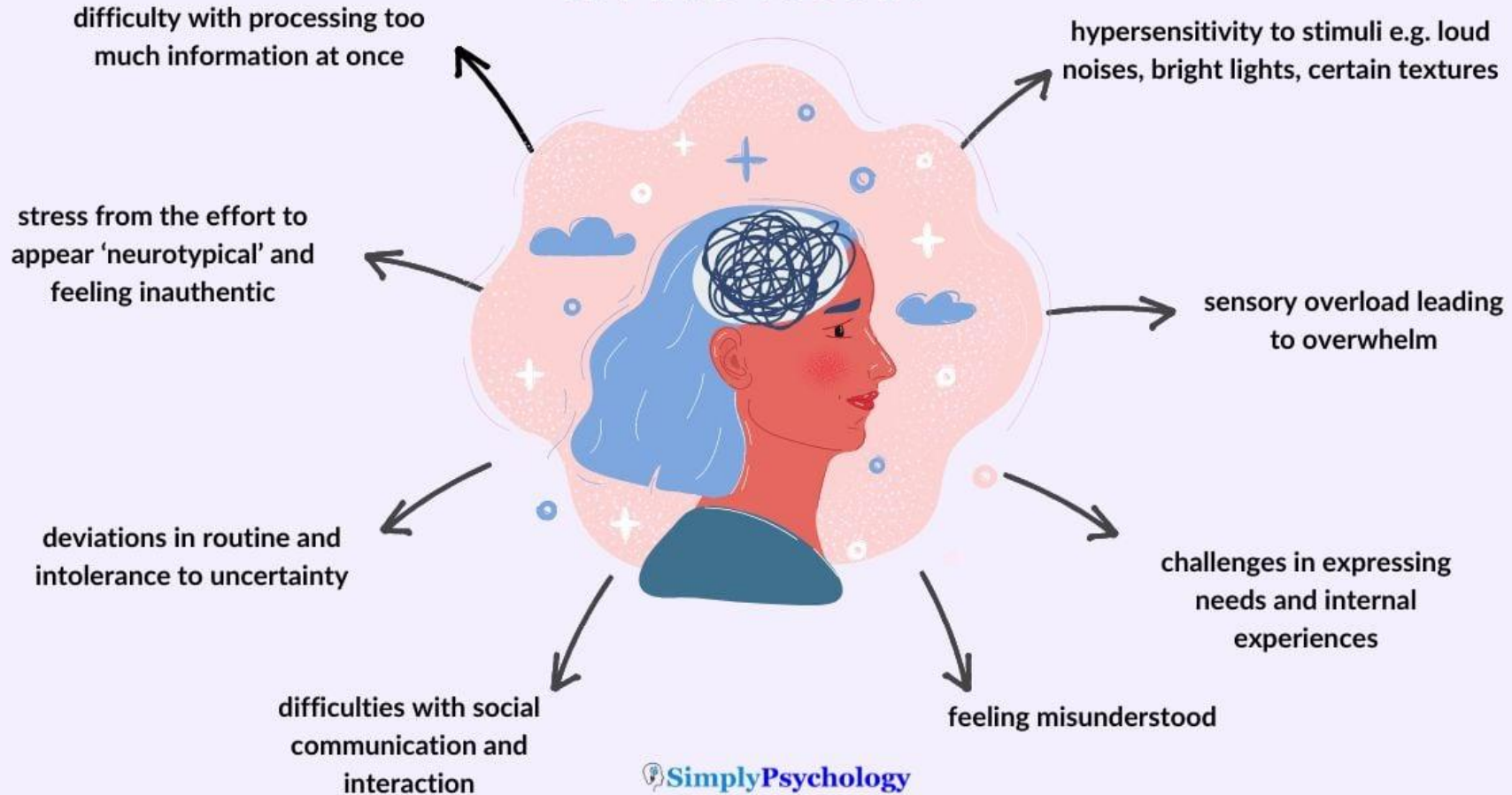
- Separation anxiety (attachment)
- Social anxiety (relational)
- Performance anxiety (learning)
- Environmental anxiety (safety and sensory processing)

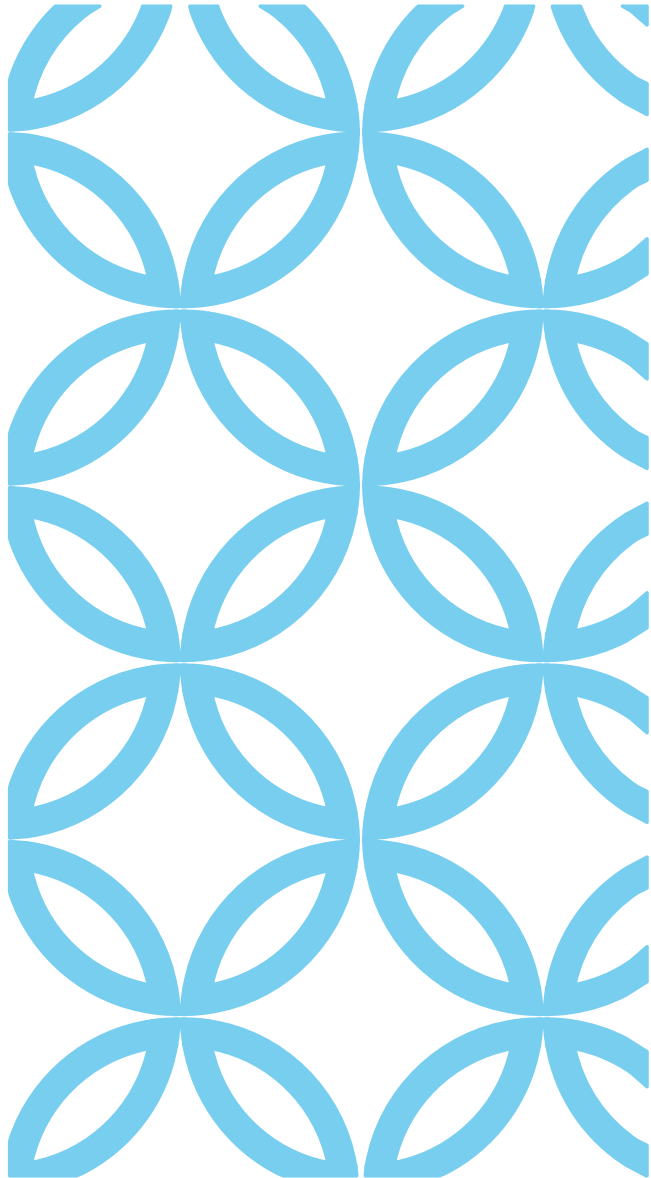
They also experience differences in relation to **managing their internal world**, including their emotions:

- Interoception
- Alexithymia
- Masking/social camouflaging



WHAT CAUSES ANXIETY IN AUTISM?





“If you think back to the last time you were really stressed about a specific event, then consider the duration over which that event impacted on you; and then doubling that, trebling that, even multiplying that by ten, this could be the duration of an event that causes anxiety for an autistic child”

(Avoiding Anxiety in Autistic Children, Dr Luke Beardon, 2020, p. 29).

HOW MIGHT ANXIETY PRESENT?

Anxiety in children (just like in adults) can present in many different ways.

Not everybody becomes outwardly upset, fearful or tearful.

Becoming very angry or displaying behaviours such as becoming controlling or avoidant can 'hide' the anxiety that is happening underneath.

Anxiety presents itself in many different ways...

www.thepathway2success.com

The desire to control people and events		Difficulty getting to sleep		Feeling agitated or angry	
	Defiance and other challenging behaviors		Having high expectations for self, including school work & sports		Avoiding activities or events (including school)
Pain like stomachaches and headaches		Struggling to pay attention and focus		Intolerance of uncertainty	
	Crying and difficulty managing emotions		Over-planning for situations and events		Feeling worried about situations or events

www.thepathway2success.com Clipart by Kate Hadfield & Sarah Pecorino

WHAT IS IT LIKE TO EXPERIENCE A PDA DRIVER AS AN AUTISTIC CHILD / YOUNG PERSON?



“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.” – Tally, Can You See Me?

“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” – Holly, PDA Society

<https://www.pdasociety.org.uk/resources/my-experience-of-pathological-demand-avoidance/>

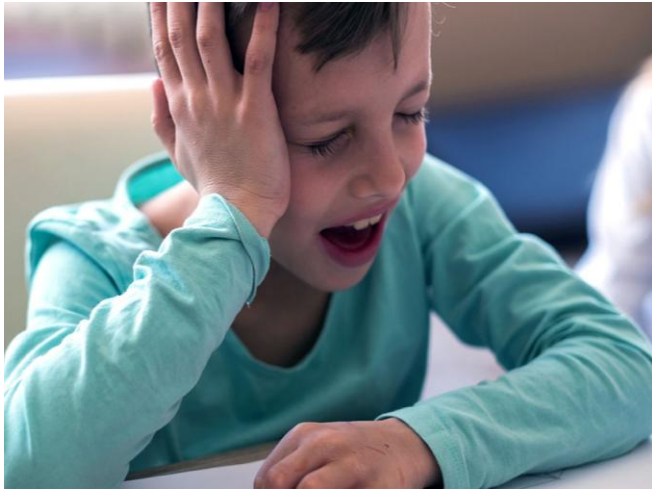


ISAAC: AN 18 YEAR OLD WITH AUTISM AND A PDA PROFILE

My Experience of Pathological Demand Avoidance (PDA)



MAIN FEATURES OF A PDA PROFILE



Resisting and avoiding the ordinary demands of life - the key words here are ‘ordinary demands’, so this might include getting up, getting dressed, eating a meal, or washing. Significantly, it includes things that someone might want to do/enjoy.

Experiencing intense emotions and mood swings – meaning difficulties with emotional regulation, rapid mood swings, impulsiveness, and unpredictability.

A need for control which is often driven by anxiety or an automatic ‘threat response’ in the face of demands (The PDA Society, 2021).

A tendency not to respond to conventional approaches in parenting, teaching or support.

MAIN FEATURES OF A PDA PROFILE

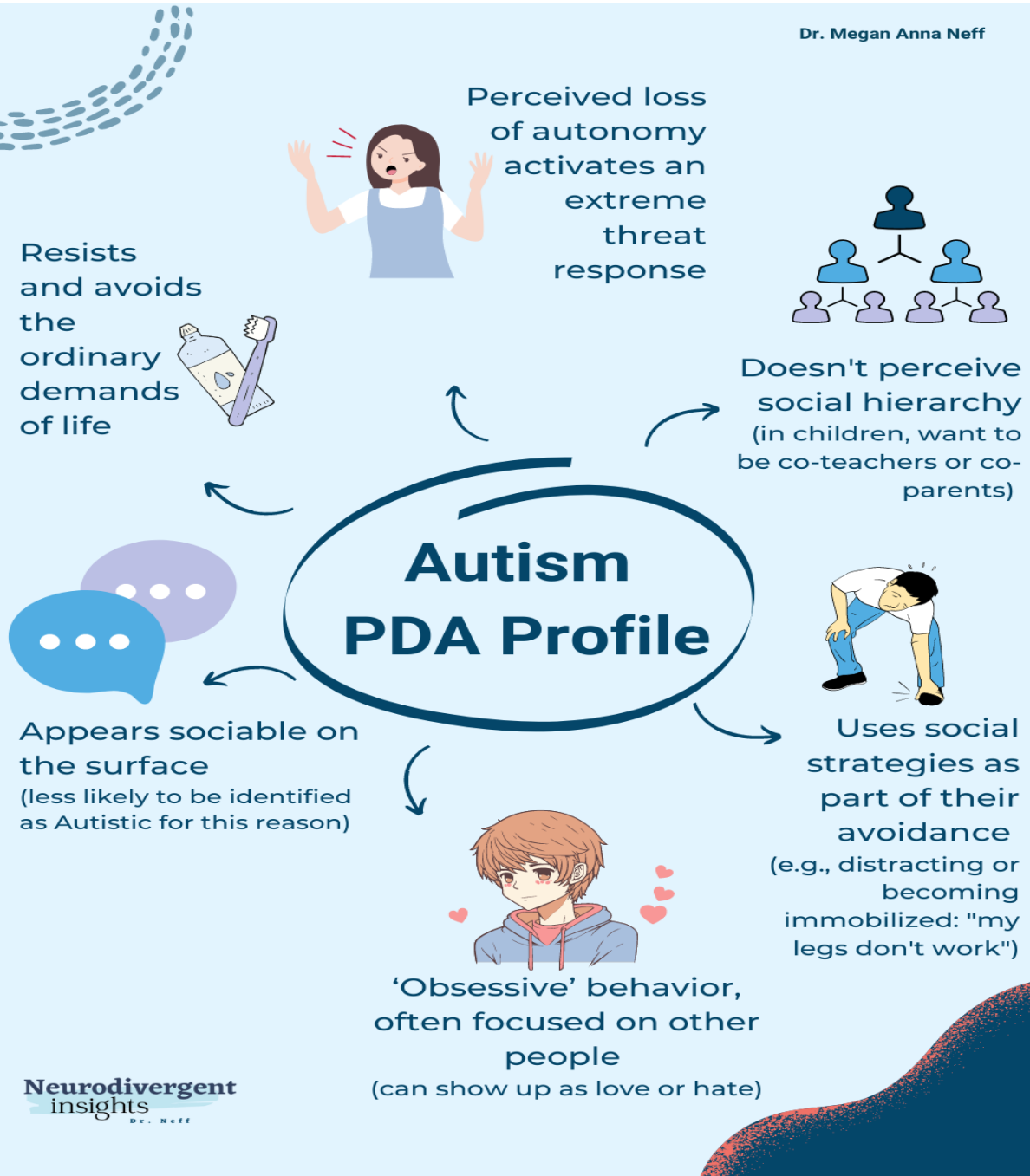
Appearing comfortable in role play, pretence & fantasy – this can sometimes be to an extreme extent with other personas (be that a person or an animal) being adopted for a prolonged period. The line between fantasy and reality can sometimes become blurred.

Dedicated and focused interests, often focused on other people – “repetitive or restrictive interests” are often social in nature, relating to real or fictional people.

Using ‘social’ strategies as part of the avoidance – this means not just saying “no”, withdrawing, shutting down or running away, but a variety of avoidance approaches including distraction, making excuses, physical shutdown, withdrawing into fantasy, procrastination, controlling, reducing meaningful conversation, or masking.

Appearing sociable, but lacking some social understanding – meaning that individuals may appear more sociably ‘able’ than one might expect (with, for instance, more ‘socially accepted’ eye contact or conversational skills) but that this may mask underlying differences/difficulties in social interaction (for instance, not seeing any difference between themselves and an authority figure) and communication (for instance, whilst an individual may be very articulate, their understanding of others may not be so robust).





KEY FEATURES OF PATHOLOGICAL DEMAND AVOIDANCE (PDA)

USES SOCIAL STRATEGIES AS PART OF THE AVOIDANCE

RESISTS AND AVOIDS THE ORDINARY DEMANDS OF LIFE

APPEARS SOCIABLE ON THE SURFACE, BUT LACKING DEPTH IN UNDERSTANDING

SOMETIMES APPEARS COMFORTABLE IN ROLE PLAY AND PRETEND, (SOMETIMES TO AN EXTREME EXTENT)

EXPERIENCES EXCESSIVE MOOD SWINGS AND IMPULSIVITY

'OBSESSIVE' BEHAVIOUR, OFTEN FOCUSED ON OTHER PEOPLE



BUT REMEMBER, WE'RE ALL INDIVIDUALS.....

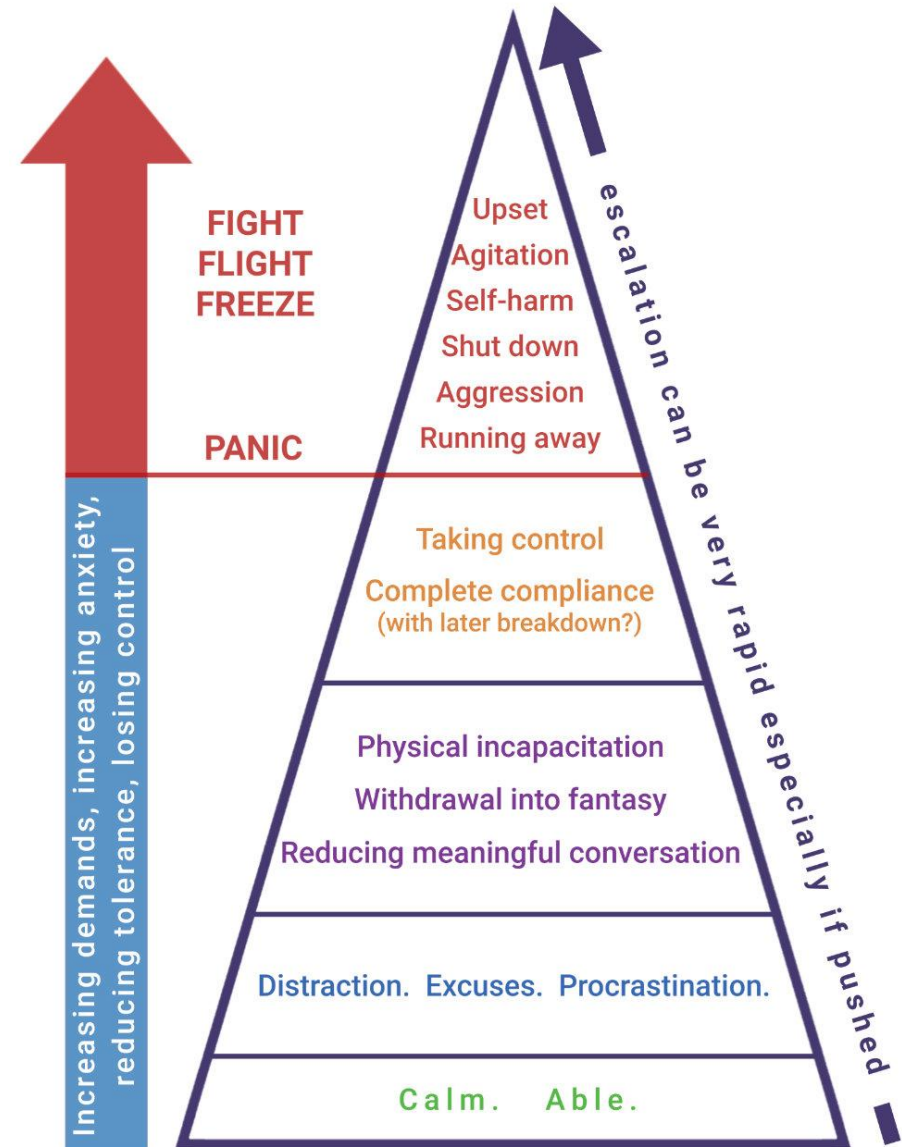
Like all autistic children, those with a PDA profile will likely present differently from each other, and present differently themselves depending on a range of factors:

- general health and mental wellbeing (including sleep and eating, any history of trauma)
- social factors
- environmental factors
- tolerance levels (e.g. for sensory and social demands)



A PDA PROFILE:

AVOIDANCE ESCALATION



WHEN DEMANDS BECOME GREATER THAN A CHILD'S ABILITY TO MANAGE THEM.....

Avoidance no longer works, and so a child reaches a state of overwhelming anxiety without a strategy to manage it.

Their bucket overflows and they reach a state of overwhelm / panic.



PANIC = MELTDOWN

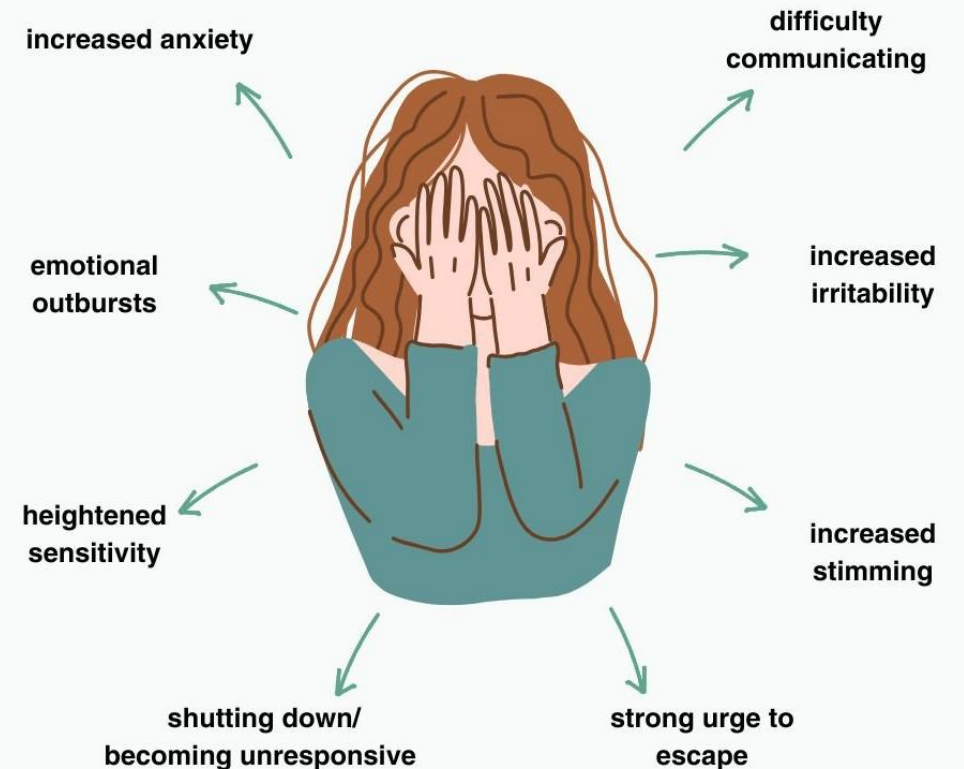
Meltdowns are a response to being overwhelmed and can be an outward or inward (result in a 'shut down') response.

Meltdowns are **not a deliberate action in order to make something happen or change.** They are an emotional, anxiety-driven reaction to being overloaded. They are extremely distressing to the person experiencing them as well as the person witnessing and supporting them.

Fear or intense anxiety is the primary driver behind a meltdown, which explains how they are linked to the 'flight, fight, freeze' responses.

Meltdowns are sometimes likened to a **panic attack.**

SIGNS OF AUTISTIC MELTDOWN



During emotional ‘meltdowns’ children’s brains and bodies are in an automatic STRESS RESPONSE. They are therefore likely to experience:

- Raised anxiety
- Physical symptoms of fear like sweating, nausea/vomiting, increased heart rate
- Limited awareness of their surroundings
- Lower ability to process information
- Lower ability to communicate (particularly with words)
- Increased risk of harming self, others or equipment/environment
- Increased likelihood of getting into conflict
- Lower ability to make choices or to reason

They cannot understand, make sense of or explain WHY they are behaving the way they are.

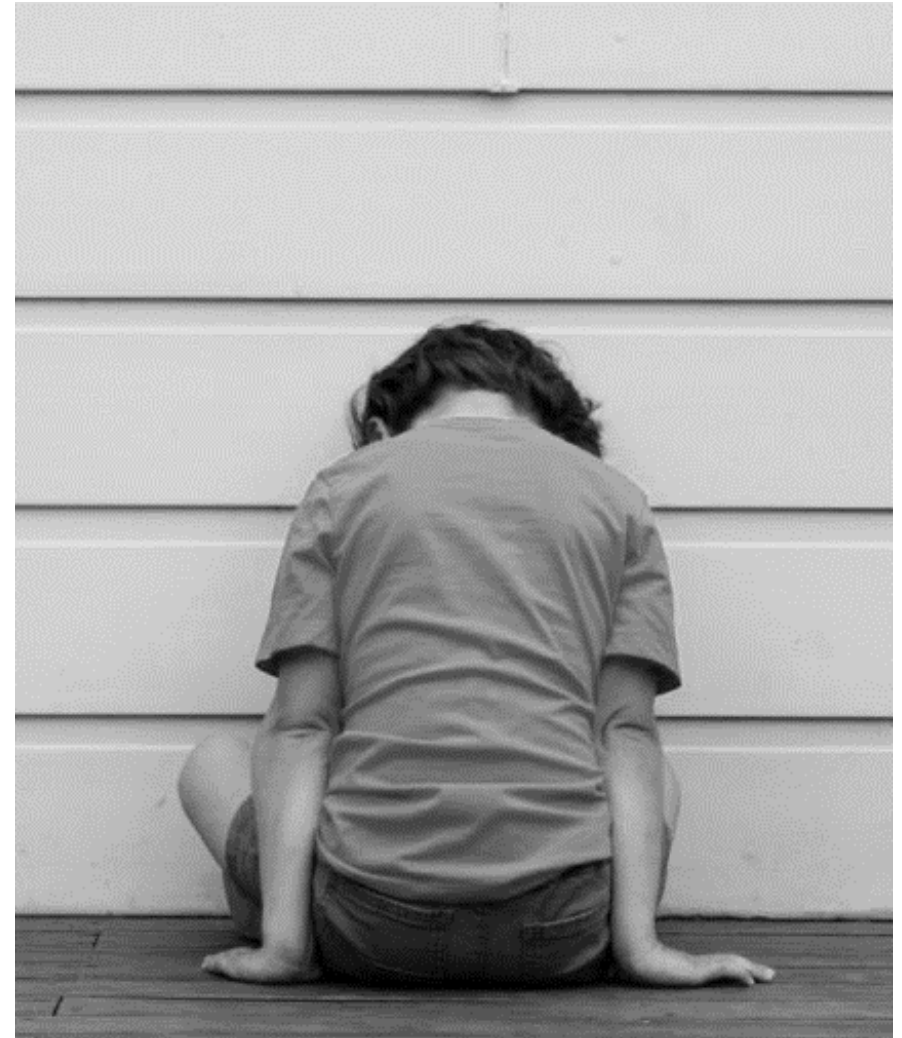
It can take a long time to return to a calm state.



A CHILD'S EXPERIENCE OF MELTDOWN

“There’s something pushing in on me. Squashing me and trapping me. I feel like I need to escape or I will explode. If I can’t get away, I start to implode”

“I feel like I am sinking. I usually lie on the floor and I cry. I don’t want to be left on my own because I am scared. But I don’t want anyone to talk to me or ask me to do anything. I want to be with someone who I like. Someone who will sit with me and squeeze my hand and arm when I put it out to them. When it’s over I am really tired and thirsty”

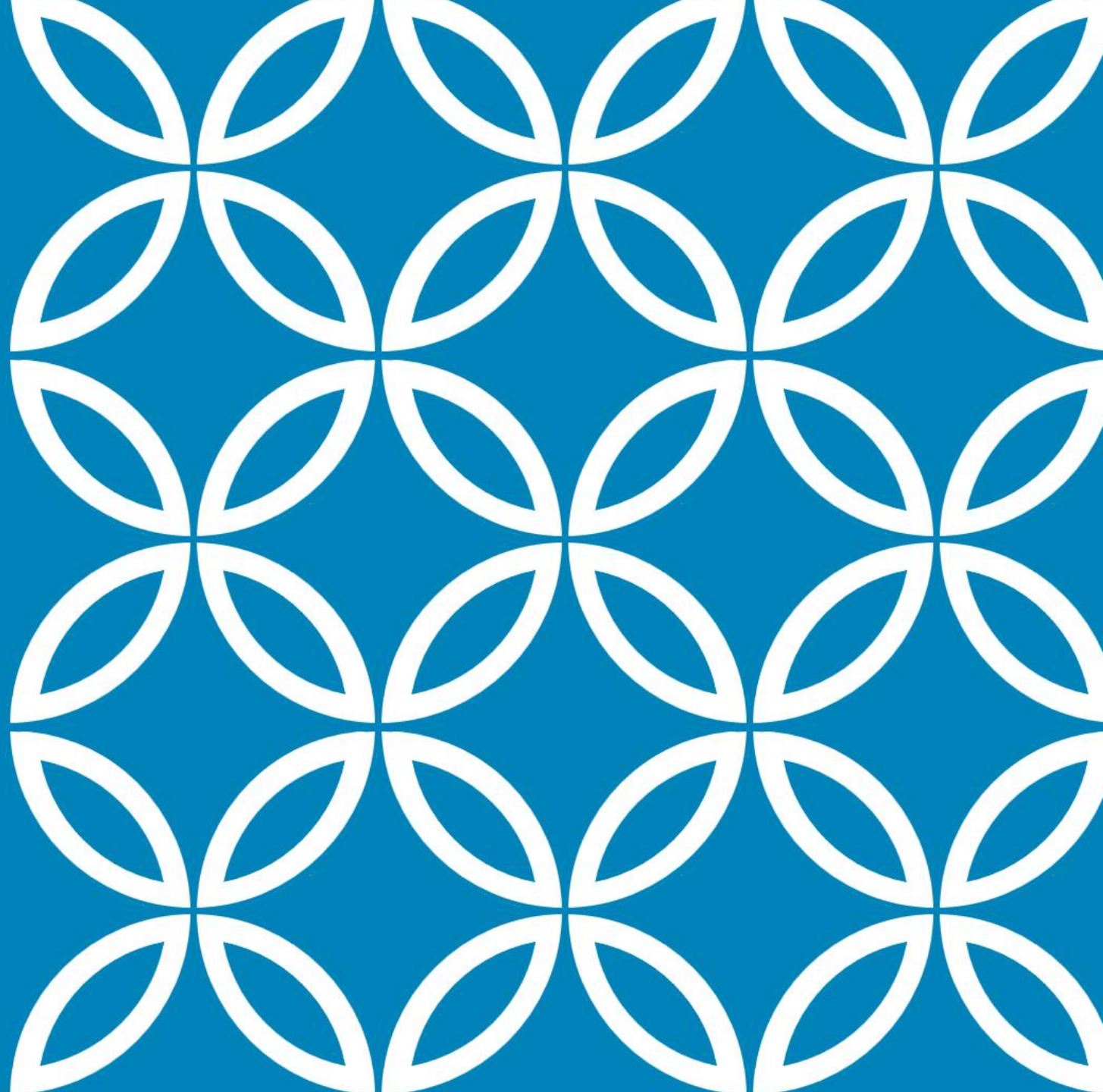




COMFORT BREAK

**PLEASE TAKE 10
MINUTES TO HAVE A
BREAK, GET A DRINK
AND GET READY FOR
THE SECOND HALF
OF THE SESSION**

**PART 2: HOW CAN
WE SUPPORT
CHILDREN WITH
AUTISM AND A PDA
PROFILE?**

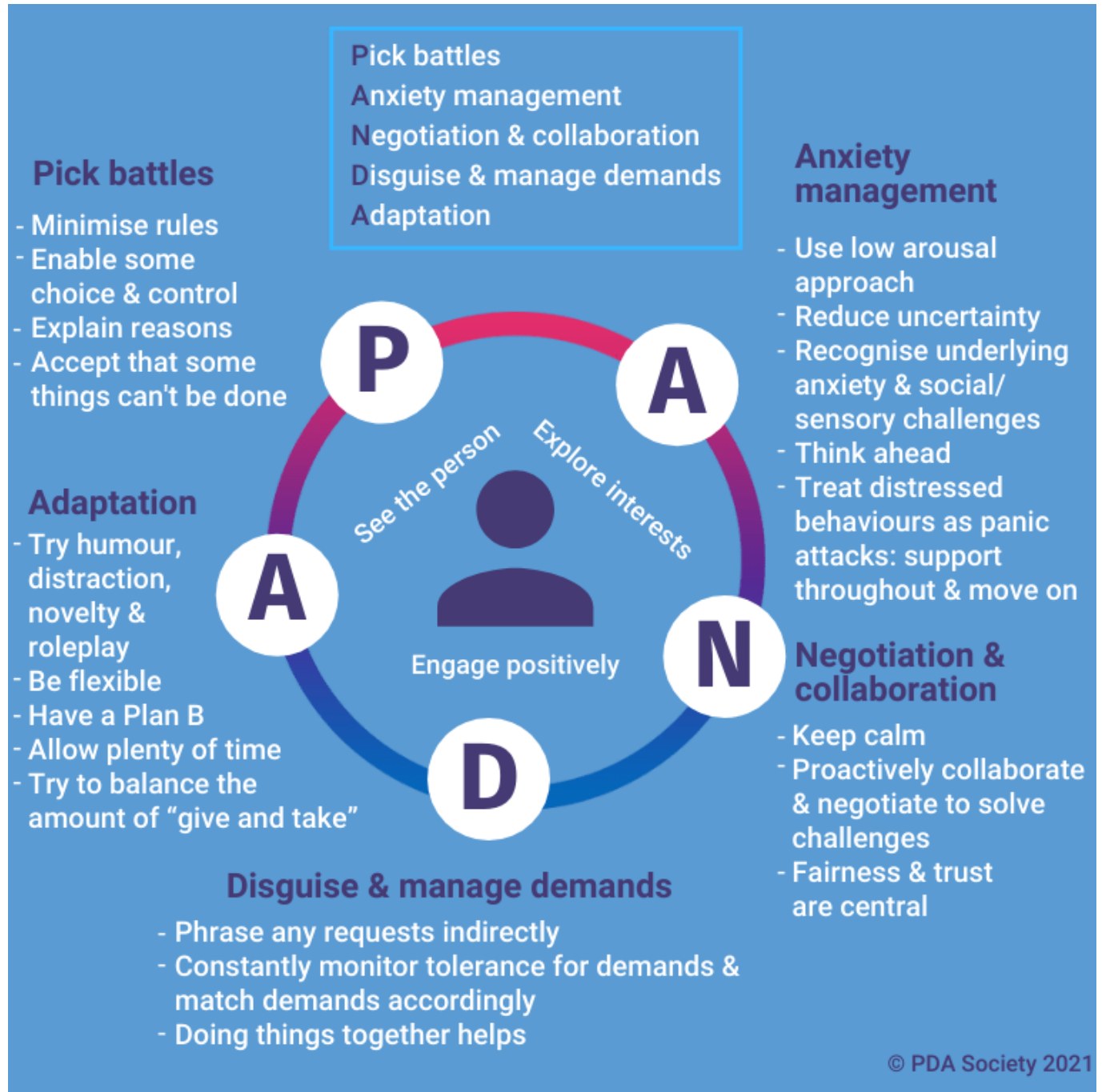


PRINCIPLES OF SUPPORT FOR PDA

Conventional approaches based on firm boundaries and the use of rewards, consequences and praise, or approaches often recommended for autism (such as routine, structure and predictability) can often be ineffective and even counter-productive for a PDA profile/driver.

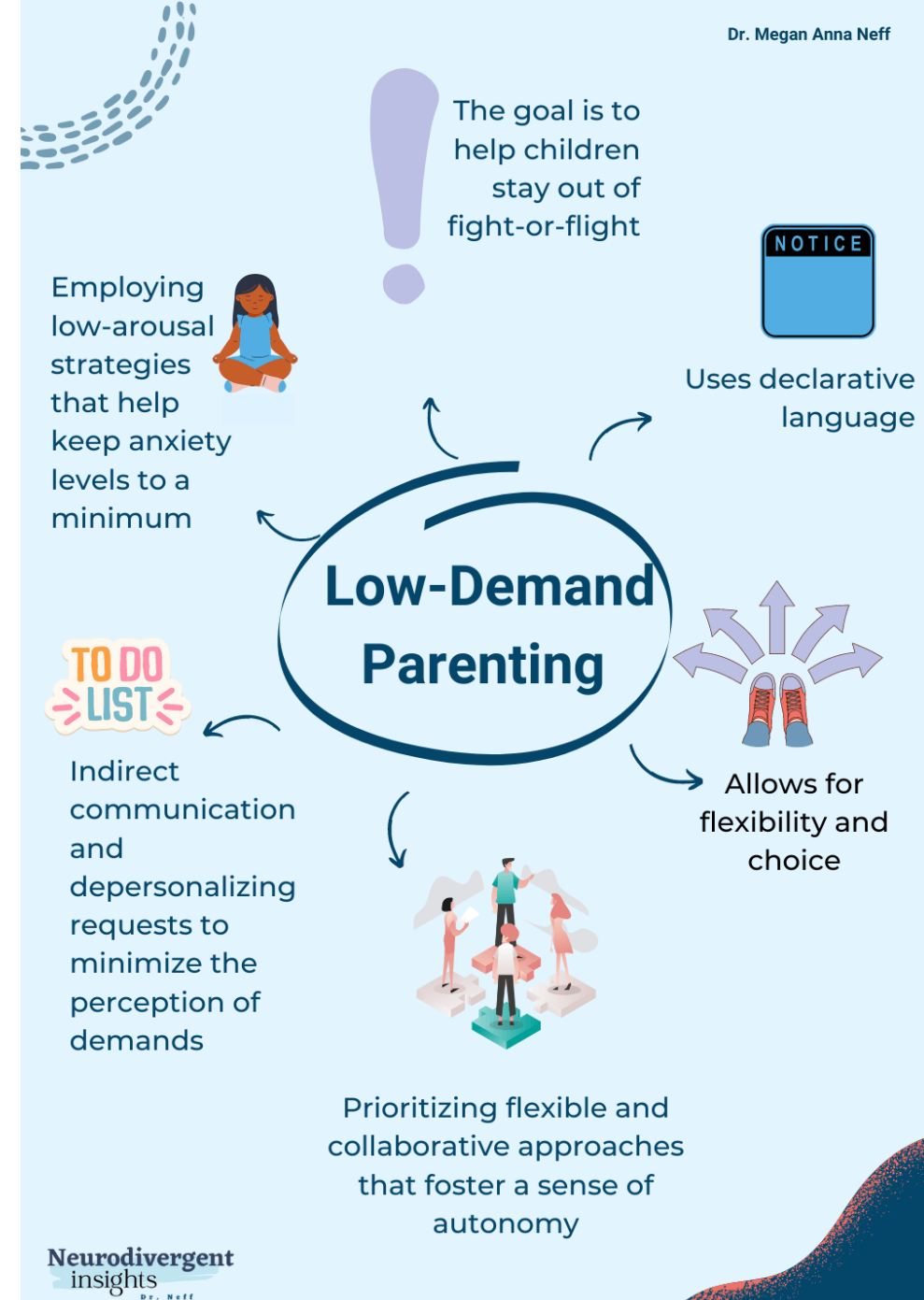
Low arousal approaches, which keep anxiety to a minimum and provide a sense of control, are good starting points when thinking about what works for PDA presentations. A partnership based on trust, flexibility, collaboration, careful use of language and balancing of demands works best.

Key supportive strategies



PICK YOUR BATTLES

- Prioritisation
- Keep calm and carry on
- Offering choices
- Be flexible
- Balancing tolerance and demands
- Low-demand NOT no-demand (lower demand vs higher demand)



PRIORITISATION

What are the areas that are most important for you to work on for / with your child?

A simple RAG (**RED**, **AMBER**, **GREEN**) rating approach can help to decide which priorities to start with and which ones to let go of, for now....

For example, if your child is finding it difficult to sleep and their tiredness is impacting on everyday life this could be the **RED** priority

If your child is 'fussy' with eating and won't eat a 'whole' meal, but they eat enough during each day, and their diet is varied enough, this could be a **GREEN** priority for now



Higher Demand	Lower Demand
Instructions <i>Get out your book and turn to page 5</i>	Statement <i>The thing I'm looking at is on page 5</i>
Using rewards <i>If you do this, I'll give you a sticker</i>	Not using rewards <i>You can have a sticker if you want</i>
Adding emotional pressure <i>It will make me sad if you don't do this</i>	Reducing emotional pressure <i>You can do this or not, I'll be okay either way</i>
Expecting them to join you <i>Can you put your tablet down and do this now?</i>	Joining them where they are <i>You're playing Minecraft, is that your house?</i>
Not giving them the option <i>You need to do this right now</i>	Building in a get out clause <i>You could do this or we could do something else instead</i>
Lots of choices <i>How about doing X, Y or Z?</i>	One choice at a time <i>We could do X</i>
Authoritative <i>You need to stop doing that right now</i>	Collaborative <i>We've got a problem because you can't keep doing that, I wonder what we could do instead</i>
Threats <i>If you don't do this, then you won't be allowed to have your iPad</i>	Reducing the threat on purpose <i>I won't be taking your iPad away. Let's think together about how we're going to do this</i>
Rigidity <i>We're going to sit here until you do it</i>	Flexibility <i>We can go somewhere else and come back later</i>
Adding an expectation <i>I've got a great idea. I'm sure you're going to love this</i>	Reducing expectations <i>I have an idea. You might like it or you might have a better idea</i>

ANXIETY MANAGEMENT

Trusted / safe adult support (*relational anxiety*)

Establish a “safe space”

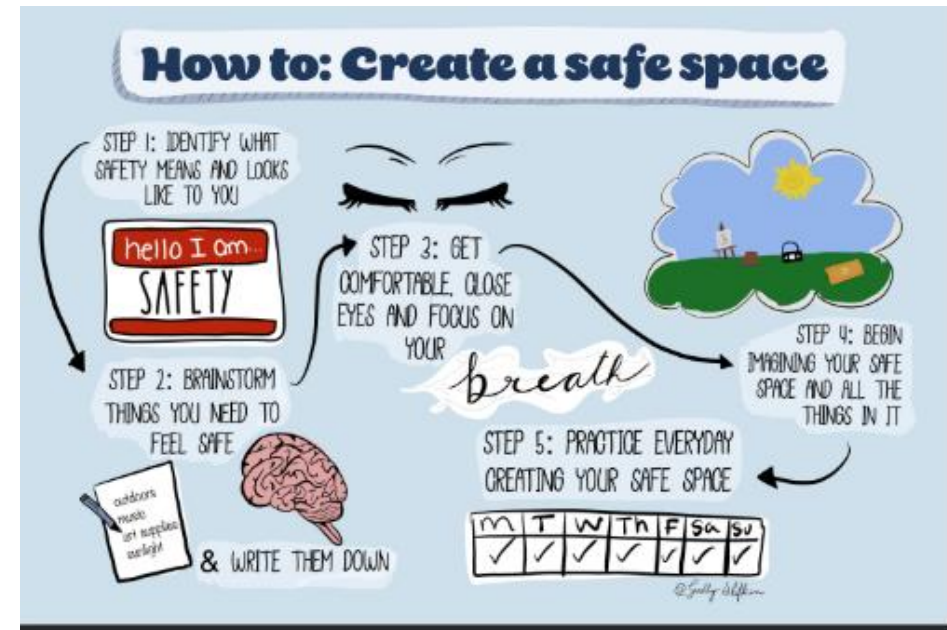
Maintain a calm approach

Reduce uncertainty / increase predictability (*environmental anxiety*)

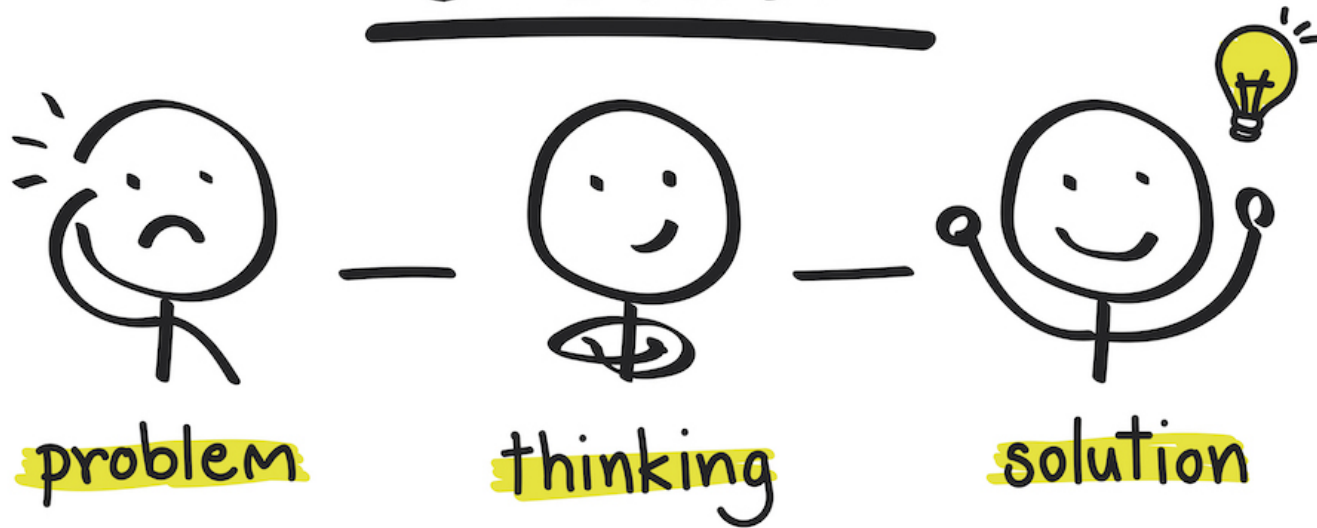
Support through physiological responses, such as space to breathe / mindfulness approaches

Emotional regulation support – identifying, labelling and understanding emotions (*emotional anxiety*)

Complete a sensory audit/profile – are underlying sensory differences leading to overwhelm (*sensory anxiety*)



PROBLEM SOLVING



NEGOTIATION & COLLABORATION

- Agreeing non-negotiable boundaries
- Problem-solving approach
- Choices and prioritising
- Visuals and checklists may be helpful, but explore this as it can also add to further demands
- Explaining reasoning (the 'why' / the purpose)



A MASTER OF DISGUISE

DISGUISE & MANAGE DEMANDS

- Reducing the perception of demands
- Phraseology and tone
- Rephrasing
- Indirect communication / Declarative Language
- De-personalising

UNDERSTANDING PATHOLOGICAL DEMAND AVOIDANCE WHAT ARE CONSIDERED DEMANDS?



DESIGNED BY SUNSHINE SUPPORT
using information from & the experienced shared by PDA young people
www.sunshine-support.org

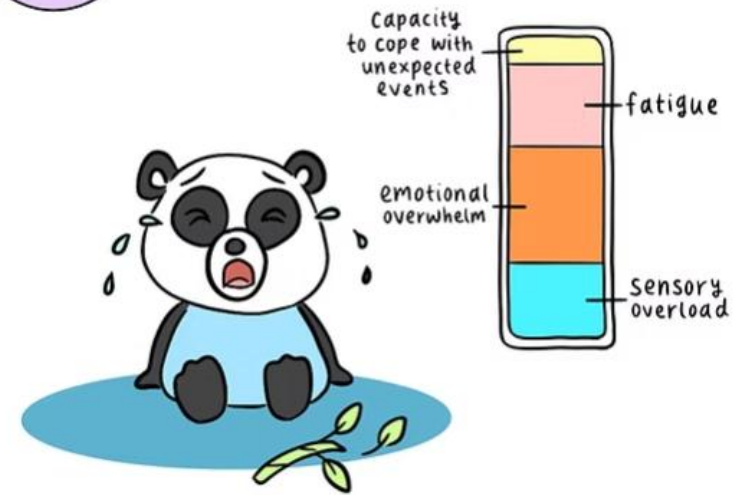
DYNAMIC / FLUCTUATING CAPACITY TO COPE



So what does it mean?



This time, Panda was too tired and overwhelmed to cope with this unexpected situation.



Check his bar - this response is not a choice. He's coping the best he can.



DECLARATIVE LANGUAGE: TOP TIPS

This involves changing the way you use language to communicate with your child.

It takes time to make change, so be kind and patient with yourself.

If at first you don't succeed, try, try and try again....

Declarative Language Quick Tips to Start

Pause and Observe: Before speaking, take a moment to observe the situation. This helps you comment on the environment instead of directing behavior.

Express Curiosity: Use phrases like "I wonder..." or "I notice..." to spark curiosity and invite your child to think and respond.

Be Specific: Mention specific things you see or feel. For example, "I see your shoes are still by the door," instead of "Put your shoes away."

Encourage Problem-Solving: Ask open-ended questions that encourage your child to find solutions, like "What do you need for your homework today?"

Avoid Yes/No Questions: Frame your language to promote more than a yes/no response, which fosters richer communication and decision-making.

DECLARATIVE LANGUAGE

DECLARATIVE LANGUAGE EXAMPLES

- "Do you want a snack?" → "Let's have a snack!"
- "Where's your backpack?" → "I wonder where your backpack is..."
- "What book do you want to read?" → "I forget which book you said you wanted to read."
- "Grab a fork." → "I think we might need some forks."
- "Wash your hands." → "Your hands look dirty."
- "Feed the dog." → "The dog looks hungry."

DECLARATIVE LANGUAGE WORDS & PHRASES TO TRY

- Notice
- Feel
- See
- Hear
- Think
- Imagine
- Forget
- Wonder
- Know
- Remember
- Perhaps
- Maybe
- I don't know
- Might
- Sometimes
- What a great question
- Let's find out together
- I'm not sure
- I like
- I don't like
- Let's
- I, my, me, mine
- We, us
- Emotion words



four things to
tell your ADHD child
after school using
declarative language

Statements that share feelings or experiences.

Example: "I thought of you today when I saw a Minecraft t-shirt at Target!"

Commenting or describing.

Example: "My day was a little hectic. I got to work and realized I didn't bring my laptop with me!"

Connection or praise.

Example: "You're so great at organizing! I was wishing I had your help cleaning out the pantry."

Think-aloud or problem solving statements.

"I wonder the best way to handle our afternoon. Today we have golf, and we have to finish your diorama."

MEALTIME LANGUAGE MATTERS!

declarative language

- inviting
- honors your child's in-the-moment cues
- kids can join, observe, or say "no"
- builds trust and confidence
- creates safety and positive experiences at mealtime



imperative language



- puts pressure on kids
- increases stress around mealtime and food
- does not take into account the child's cues in the moment

declarativelanguage.com

ACTIVITY 2: DECLARATIVE LANGUAGE

TALK TO THE PERSON NEXT TO YOU AND HAVE A GO AT CHANGING YOUR LANGUAGE WHEN TALKING TO YOUR CHILD FOR:

- * GIVING AN INSTRUCTION
- * GIVING PRAISE
- * ASKING A QUESTION



ADAPTATION

Get to know things from the child's perspective

Allow plenty of time and flexibility

Focus on the long-term objective of building a child's ability to cope rather than short term compliance

Distracting/turning things into a game

Special interests and creativity

Using humour/novelty

Support sensory needs

Positives of Special Interests

(Grove et al. 2018; Nowell et al. 2020)

They are associated with good well-being

They bring a lot of joy and rarely affect functioning

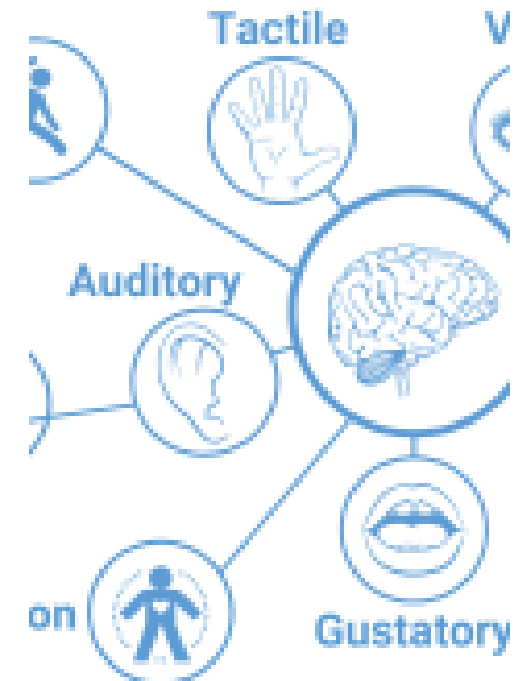
They can lead to good careers and positive effects

Can provide a community of those with the same interest, reducing loneliness

A way of escaping and recharging, or regulating after meltdowns or overwhelm

They can provide structure or certainty amongst unfamiliarity and unpredictability

@itsemilykaty



TRY TO AVOID...



BUILDING UP TO
REWARDS



PERSONALISED PRAISE



INFLEXIBLE SANCTIONS
OR CONSEQUENCES

THE CHILD'S VOICE.....

A CHILD'S VOICE

I HAVE PDA, I NEED YOU TO KNOW...

Pathological Demand Avoidance/Persistent Drive for Autonomy

"I live with very high anxiety, even when I look calm on the outside"

"When something feels like a demand, my body reacts with panic before I can think it through"

"I want to do the right thing and meet expectations, but my anxiety often gets in the way"

"I am not choosing to resist — my nervous system is trying to protect me"

"I am trying all the time, even on days when it doesn't look like it"

"I may avoid, say no, joke, or shut down because I feel overwhelmed, not because I don't care"

"I need patience while I calm my body — I can't learn or problem-solve when I'm anxious"

"I need reassurance and safety before I can cooperate or engage"

"I want to be part of finding solutions that work for me, not done to me"

"I feel safest when things are framed as choices, teamwork, or invitations"

"I need you to see my effort, not just my behaviour"

"I often feel guilty or ashamed afterwards because I know my reactions are hard for others"

THE IMPORTANCE OF TAKING CARE OF YOURSELF

PUT YOUR OXYGEN MASK ON FIRST

Better Capacity to Problem Solve

More Bandwidth to Care for Others



ficuspsych.com

Less Burnout

Models Self-Care, Coping, and Resiliency

8 types of self care

PHYSICAL



nutrition
exercise
sleep

MENTAL



mindfulness
self-talk
therapy

EMOTIONAL



gratitude
triggers
journal

SPIRITUAL



meditate
nature
yoga

INTELLECTUAL



read
learn
hobbies

ENVIRONMENT



clean
safety

SOCIAL



boundaries
connection

FINANCIAL



budget
save

QUESTIONS



RESOURCES

* **'Can't Not Won't – A Story About a Child Who Couldn't Go to School'** by Eliza Fricker (parent perspective)

* **'The Teen's Guide to PDA'** by Laura Kerbey

* **'The Family Experience of PDA'** by Eliza Fricker (parent perspective)

* **'The Teacher's Introduction to Pathological Demand Avoidance – Essential Strategies for the Classroom'** by Clare Truman (teacher's perspective)

* **'The Educator's Experience of Pathological Demand Avoidance'** by Laura Kerbey (educator's perspective)

* **'Pretty Darn Awesome'** by Lauren O'Grady

* **'Wonderfully Wired Brains: An Introduction to the World of Neurodiversity'** by Louise Gooding and Ruth Burrows

(informative and inclusive children's guide to neurodiversity for those not in the know and to inspire children who are neurodivergent).

* **Neurowild** - [Home](#) | [NeuroWild](#)

