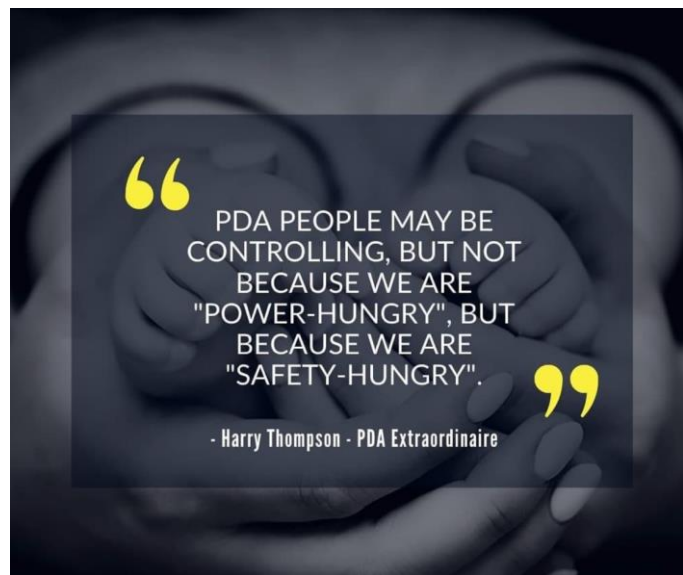


Pathological Demand Avoidance (PDA) and Autistic Demand Avoidance

Pathological Demand Avoidance (PDA) and Autistic Demand Avoidance are terms which relate to an uncontrollable and unintentional compulsion to avoid demands placed upon you and to refuse to comply with (even simple) requests. People who have what we regard as a “strong PDA profile” often appear oppositional to others and can look like they are being excessively controlling. However, they are not trying to be difficult, nor choosing to be defiant. The nature of this profile means the person is fighting for survival and has adopted a necessary coping mechanism to help protect themselves and protect their mental health. PDA is not listed in the DSM-V



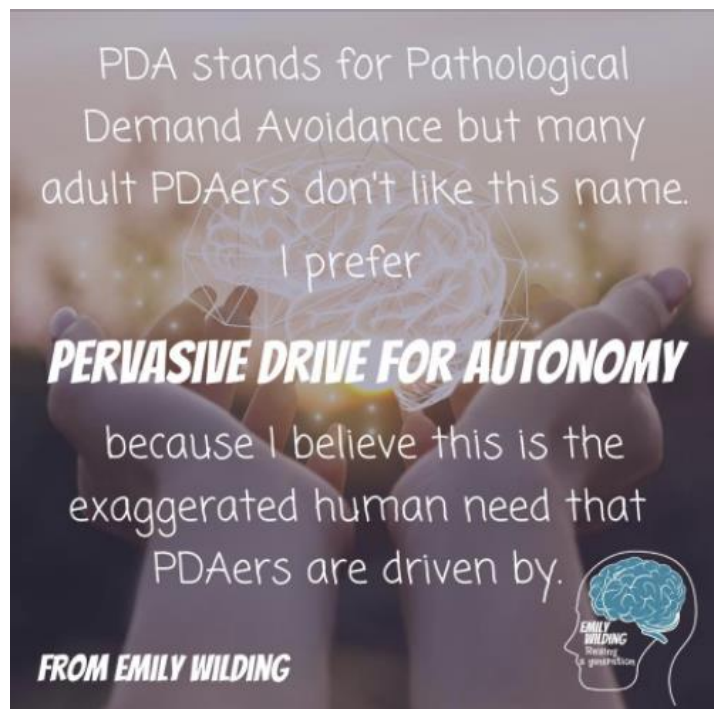
(version 5) as a separate diagnosis and therefore will not be listed as a ‘diagnosis’. Absence of this being listed in a person’s diagnostic profile doesn’t mean the person doesn’t have a PDA profile.

Autistic Demand Avoidance exists as part of the Autistic neurotype and is often more internalised. Those with Autistic Demand Avoidance are likely to struggle when they feel controlled by others and might avoid social situations, task lists, routines, but can manage some demands and don’t feel they need to always be in control. A lot of people with strong rejection sensitive dysphoria will live with Autistic Demand Avoidance, but not Pathological Demand Avoidance, as their need for acceptance and validation from others is often more of a driver than fighting feelings of being controlled by others, or by situations.

PDA and Austistic Demand Avoidance (ADA) came to life and was identified as being a response to the trauma endured by Autistic individuals who are forced to navigate their needs in a predominantly neurotypical (NT) world. From birth, the (often) strong sensory profile and aversion to social expectations and pressures that the Autistic person has is ignored by NT people, professionals, teachers, and environments. Autistic people are put into positions that are aversive to their sensory needs and thus cause them significant pain and feelings of a loss of control and hurt. In response to this pain and trauma, many Autistic people develop a 'say no first' attitude to manage themselves and to protect their sensory and emotional needs.

Some of the most difficult things for anyone with a PDA profile are:

- Being told what to do.
- Having to change from one activity to another.
- Doing things they don't want to do.
- Being around people they don't want to be around.
- Following instructions.
- Asking for help from anyone.
- Answering questions for any reason.
- Getting scalded / getting reprimanded for any reason.
- Any kind of restriction, limitation or transition is so much harder.
- Anything that leads to feelings of a loss of control.



PDA can lead to exhaustion, to burnout and can increase the sensory sensitivities of every other part of your body and processing.



Helpful approaches for a PDA profile of autism

Conventional support strategies, including those often recommended for autism, are often ineffective and counter-productive with a PDA profile. In place of structure, routine, firm boundaries, praise, rewards/consequences, is a person-centred approach based on negotiation, collaboration and flexibility.



The PDA PANDA symbolises the need to tailor the

environment to meet needs and our P A N D A mnemonic is a simple reminder of helpful approaches.

For more information please visit www.pdasociety.org.uk

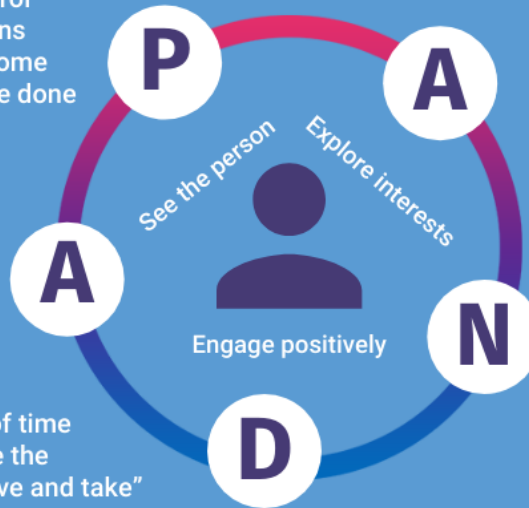
Pick battles

- Minimise rules
- Enable some choice & control
- Explain reasons
- Accept that some things can't be done

Adaptation

- Try humour, distraction, novelty & roleplay
- Be flexible
- Have a Plan B
- Allow plenty of time
- Try to balance the amount of "give and take"

- Pick battles
- Anxiety management
- Negotiation & collaboration
- Disguise & manage demands
- Adaptation



Anxiety management

- Use low arousal approach
- Reduce uncertainty
- Recognise underlying anxiety & social/sensory challenges
- Think ahead
- Treat distressed behaviours as panic attacks: support throughout & move on

Negotiation & collaboration

- Keep calm
- Proactively collaborate & negotiate to solve challenges
- Fairness & trust are central

Disguise & manage demands

- Phrase any requests indirectly
- Constantly monitor tolerance for demands & match demands accordingly
- Doing things together helps

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People with PDA will struggle to manage change and expected transitions to different activities and environments at times. Change is difficult to most Autistic children and adults and can cause overwhelming feelings of losing control, as well feeling overwhelmed by changes to the sensory input they are experiencing. Suggestion of change is hard to manage and can cause these feelings (of loss of control and demand avoidance) immediately.

Helping someone who's Autistic and has a PDA profile **requires the avoidance of any directions which sound like demands or requests**. Essentially you need to talk in questions, allowing the person to feel fully able to control their actions and the situation. Transition is managed (in summary) by enabling the person to prepare in their way for the transition (sometimes using a timer or discussing the necessary transition earlier so it is planned and structured), then just before the time that the transition needs to happen, the person might

need assistance to cognitively transition to a new environment or task. This will be explained further later on in this information sheet.

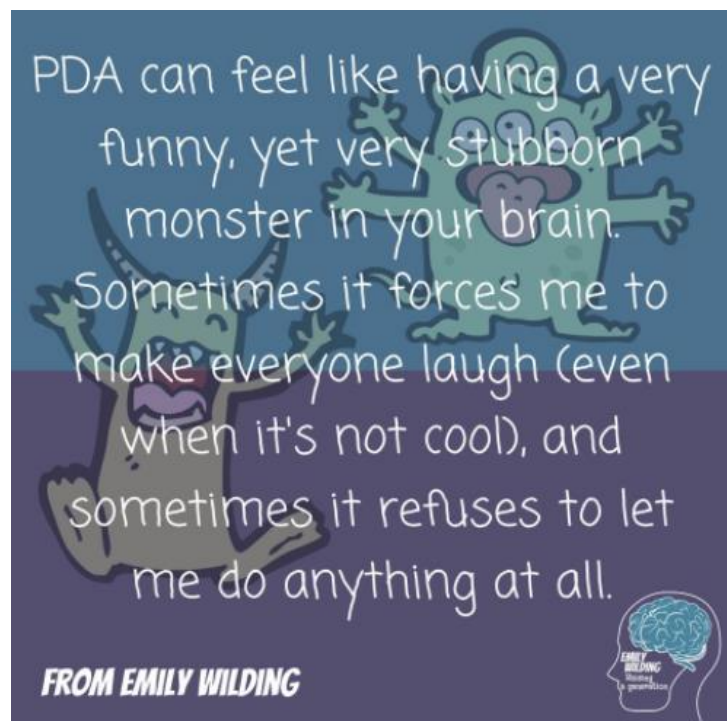
If the person has Attention Deficit Hyperactivity Disorder (ADHD) as well as PDA, transitions can be even harder. The hyperfocus which exists in a person with ADHD can make it so hard to transition the brain to a different topic. Often distractions are needed to help them shift their focus to something new.

Make sure you read the Information Sheet on Autistic Inertia as this provides information about the difficulty with transition and many strategies to manage this.

The nature of change instigates a FIGHT for survival

The mere nature of change is painful for someone with a PDA profile. Nearly any request put before them will be met with opposition as a first response. In part it is believed that this happens due to survival strategies learned by neurodivergent children born into a neurotypical world, who are faced with nothing but offensive and unhelpful demands and stimulation from birth. The stronger willed of these personalities develop the PDA profile to survive.

The primary and underpinning component of working with someone with a PDA profile is not appear as if you're making demands. Demands will always be met with avoidance. Instead, provide options for them to make decisions and have control, then ask what their decision is.



Transition is all about change and thus is one of the hardest things with people who live with a PDA profile.

Pathological Demand Avoidance (PDA) is a huge component of the lives of many Autistic folk. It often comes across as stubbornness or non-compliance, but the tendency for “no” to be the first response for many Autistic folk is not a choice, but a necessity. From day 1, being born into a neurotypical (as a majority) world, an Autistic individual is forced to fight against everything to feel regulated. This leads to an ingrained distrust of demands, expectations, and requests of others as there is a significant likelihood they will be traumatic.

PDA is a method of protecting oneself from the traumatic effects of a neurotypical world.

NO should NOT be seen as non-compliance, but instead should be respected as self-protection.

PDA needs to be considered at all times. It’s important that we don’t see resistance, control and possible hostility to be negative. Instead, this is behaviour of safety and protection for the person and is a sign that they are feeling like they need to feel in control.

Transition Management

One of the ways PDA is most evident is with regard to transitions. Transition refers to when someone has to change something. This might be changing from one task to another, or going home from work, or going to a different parent’s house. This could also be the transition to turning off the computer / devices and having dinner. Transition is change and change is super hard for some people. The pic shows the 6 different responses to change, when seen as a threat and is very specific to those who are Autistic and struggling due to PDA.



Transition or change management is important to plan and consider and presenting and highlighting change is often very unhelpful as this can increase the 'fight' response in the person and make them want to resist the change **just because it's change**. The nature of PDA means that demands or polite requests don't have to be nasty or aggressive for them to be avoided. The mere nature of change often invokes a pathological opposition which fuels the person's avoidance and fear.

Make sure you read the Information Sheet on Autistic Inertia as this provides information about the difficulty with transition and many strategies to manage this.

PDA Language – Include Natural (nor forced) Consequences

When helping someone to make choices, it's helpful to remind them of what will happen based on each of the choices they make. Natural consequences are the things that will naturally happen when someone does something.

Examples of natural consequences

- If we go out in the rain, we will get wet.
- If we are rude to our friends at work or school, they won't want to talk to us.
- If we spend our money on McDonalds or gaming, we won't have money for anything else. We WILL not be able to pay to go out with friends, we will NOT be able to pay for anything.
- If we scream loudly, someone might come and scream back at us to tell us to stop.
- If we choose to not wear a hat, we will have burnt skin from the sun which is painful, and it will hurt heaps.
- If we choose to throw that box at that person, it's likely they will be very mad at us as a result.

Natural consequences are real things that will happen in response to choices that the person makes. These are not punishments that we put in place, even though they can feel punishing. The difference with using natural consequences is that they allow you to be empathetic with the person about these consequences, while helping them experience them.

Let's have a look at some examples of using natural consequences, rather than directions. We often call this **PDA SCRIPTING**. PDA Scripting is a type of language which works well with those who have a PDA profile. It's different because it's not directional and doesn't use demands. Instead, it provides questions, choices, and reminders of what natural consequences will be.

Situation 1: The person is not supposed to spend their money on junk food and has to contribute \$50 to their household bill for food. If they don't do this their rental agreement could be terminated. Once this happens, they will have 7 days to move out and police will be called if they don't move once they are told. The person doesn't seem to be understanding this and keeps spending their money on junk food and not having the \$50 left.

Non-PDA Friendly (not helpful) way to approach this:

Me: *"You are not allowed to buy junk food. No junk food. I've told you already. Don't break the rules."*

Person: *"You're not the boss of me, I'll do what I want!"*

This approach and these comments will make the person immediately defiant, and their instinct (if PDA) will be likely to defy the person and buy the junk food anyway. Their full motivation at this point is based on proving that they are in control, not the other person.

PDA Friendly way (helping, using natural consequences) to approach this:

'Me' is in bold to help understand the two-person conversation below.

Me: *"What do you want to do? If you buy the junk food, what's your plan for paying the \$50 for your rental agreement for food? If they kick you out, what's the plan for where you are going to live?"*

Person: *"I want to buy McDonalds; it's my money and I can do whatever I want. You can't stop me."*

Me: *"I'm not trying to stop you. You can do whatever you like. But we need to find a homeless shelter urgently, as if you cannot pay the \$50 rent this week, you have 7 days to move or they said they are calling the police."*

Person: *"I don't want to move out, I hate homeless shelters, I want to stay here. Please let me stay."*

Me: *"I want you to stay too. It's not my choice though, I have no control over this. I begged for you, but they said they were clear. If you don't pay rent, you will have 7 days to move. I'm worried for you too. Let's look up homeless shelters now so you have somewhere safe to go when they kick you out"*.

Person: <crying, getting very distressed> *"I really don't want to leave my home. This is my home, I want to stay."*

Me: <comforts the person, is nurturing and gentle, with empathy in tone of voice> *"I know, I wish I could do something to help. I'm sorry. It's totally your choice at this point. If you don't pay the rent, we have to find somewhere for you to move. If you decide to not buy McDonalds and pay the rent, you're allowed to stay. It's your choice. You tell me what you want to do"*.

Person: *"I'm not talking to you anymore – I'm going to go pay my rent."*

In this scenario, the person focuses on reminding the person of the true natural consequences which will happen if they don't make the decision to use their money to pay rent. The person also displays empathy and reminds them that they will help them, regardless of the choice they make. This means that they are not focusing on changing their mind, just helping with the outcome of their decision.

Situation 2: The child is cranky and not coping at school and has decided to sit outside another classroom and make loud verbalisations and bang the wall (trying to regulate and vent frustration). He is disturbing the other classroom (with a different class and Teacher). When the child has done this previously, the other Teacher ended up coming out and telling him to leave (with a very stern voice).

Non-PDA Friendly (not helpful) way to approach this:

Me: *“I told you that you’re not allowed to be here. You have your classroom, the sensory room or the break room that you can be in when not in class. Please move to one of those places now.”*

Child: <becomes increasingly distressed> *“STOP TELLING ME WHAT TO DO, I’M NOT MOVING.”*

This non-PDA approach and these comments will make the person immediately defiant and their instinct (if PDA) will be likely to defy the person and stay in the place they are in. Their full motivation at this point is based on proving that they are in control, not the other person.

PDA way (helping, using natural consequences) to approach this:

Me: *“Jack, I know you want to stay sitting here, outside Classroom 3B, but there are children learning inside the classroom and your vocalisations are very noisy and it’s distracting them from their work. I would prefer you to go to the lunch space near room 4F where there is space for you to sit. I know you don’t want to go, so let’s talk through your options. If you stay here, then it’s very likely that the Teacher in 3B is going to be cranky that her students can’t concentrate, so she will probably come outside and be cranky that you’re very loud right now and tell you that you have to move. I know you don’t like that, but I think that’s what will happen if you stay here. Your other options are to move to the football field and find a space there or move to the lunch space near 4F which is prepared for you, or I suppose stay here and see how many Teachers come and tell you that you need to move. Can you have a think about this and tell me what you are going to do please?”*

Jack: <says nothing, sits there, appearing to ignore the conversation>

Me: *“I love those fidgets you brought in today. I also have some similar ones in the sensory room, I can’t wait to show you. I’m heading there now, there’s this green one which lights up, I’ll show you.”*

Jack: <says nothing, gets up to follow, to see the fidget that lights up>.

Situation 3: The person always goes to class the same way, around the back of one of the buildings and through the gate. However, there is a large magpie (bird) which has been

swooping everyone and they have sectioned off (blocked) this area to prevent injury to anyone using the area. The person is 'stuck' as they don't want to go a different way. When asked why they can't go around the other way, they have started making up answers to make reasons that cannot be argued (e.g., <almost crying, appearing distressed> *"I really can't walk that other way, I won't walk near those trees as they hurt my nose and make me sneeze."*)

Non-PDA Friendly (not helpful) way to approach this:

Me: *"You don't have a choice here I'm afraid. They have blocked off the other way. The trees won't hurt your nose, you will be fine. Please stop being silly and walk around this direction."*

Person: *"NO, I'M NOT WALKING THAT WAY, THE TREES WILL HURT MY NOSE, I SAID NO!!"*

This non-PDA approach and these comments will make the person immediately defiant and their instinct (if PDA) will be likely to defy the person and refuse to comply or become distressed because they feel trapped. Their full motivation at this point is based on proving that they are in control, not the other person.

PDA Friendly way (helping, using natural consequences) to approach this:

Me: *"I know you don't want to walk this different way to get to class, but they have put gates over the old way as there is a bird swooping and hurting people. If you tried to go that way, the bird will dive at your head and his beak will cut open your head – it hurts really bad, and you would cry for ages. You have a few other options you can choose from though. You could walk this way to get to the building we are going to (points different way), or I suppose you can just stay here and miss the activity we are doing. Or if you can think of another clever way to get to that building over there, can you let me know? I'm happy to help. Tell me if you think of something. I'll give you some time."*

Person: <is likely to be quiet for a few minutes, while thinking. Then may come up with their own option or one of those provided.>

If no option is agreed to, explain the natural consequences of staying where the person is (which could be that they miss the activity, if they are a child and it's at school, then their parents might be phoned etc).

Situation 4: The person is not supposed to go into another person's bedroom while they aren't home and watch their TV. If they do, the person will yell at them (and has hit them) when they get home again.

Non-PDA Friendly (not helpful) way to approach this:

Me: *"Don't go into Jack's room. You're not allowed, and you've been told this."*

This non-PDA approach and these comments will make the person immediately defiant, and their instinct (if PDA) will be likely to defy the person and refuse to comply or become distressed because they feel trapped. Their full motivation at this point is based on proving that they are in control, not the other person.

PDA Friendly way (helping, using natural consequences) to approach this:

Me: *"Are you supposed to go in there? Ok, well, it's your choice. I just need to find something for me to do this afternoon while he yells at you again. Is that all he will do when he gets home, just yell at you? Gosh... I hate it when people yell at me, but anyway – your choice."*

Person: *"Why do you need something to do, why do you think he is going to yell at me?"*

Me: *"I was told he does that every time you go in his room. Was that correct, or is that wrong?"*

Person: *"Yeah, he is really mean and yells and hits me"*

Me: *"Ok, do you want to be hit and yelled at?"*

Person: *"No of course I don't. He's mean to me."*

Me: *"Yeah, I wouldn't like that either. So, what do you want to do? Go in there and I will find something else to do while he yells at you, or make a different choice? You tell me."*

Person: *"This is stupid and unfair. I'm going to do something else."*

PDA scripting is about providing choice and control to the other person and making your comments in the form of questions but reminding the person of the natural consequences which are bound to happen, based on the choice they make. PDA scripting feels awkward to people as it's not directional and we are all so used to being directed by others. PDA scripting isn't guaranteed to produce compliance and there are times when the person will choose to

be happy with the natural consequence anyway. This is life and choice and their dignity of risk. We don't have the right to force someone to get it right every time and a person with PDA is likely to test you by making some poor choices and seeing if you take back control. This way of engaging allows you and wants you to still be sympathetic and kind. This method requires you to acknowledge that this is very hard for the person, but that they have the ultimate control. It's very important at all times that your behaviour and body language doesn't look like you're happy about this natural consequence, or it will be just like a punishment.

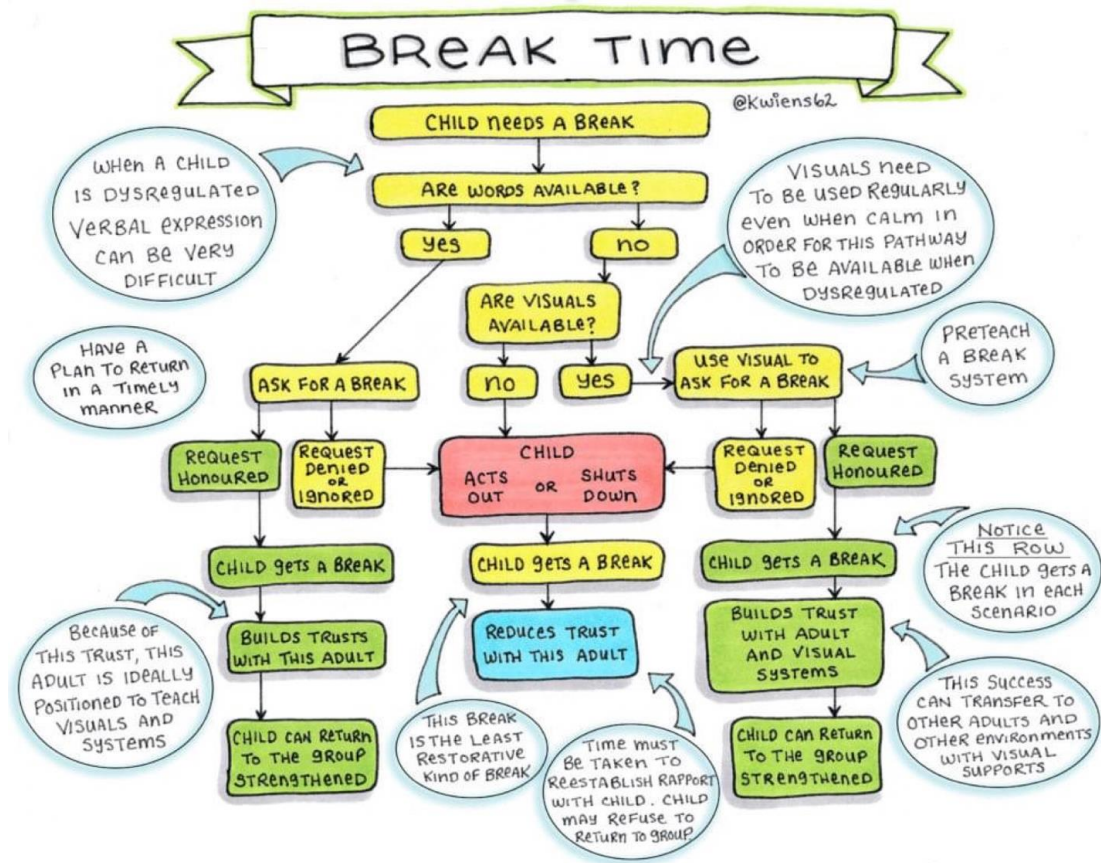
A hard thing for many to understand these days is:

People are allowed to make choices that we don't think are right for them and that we don't agree with. People are allowed to do things that might be inappropriate or wrong (to us, or to society), yet we still must uphold their right to make these choices, assert this independence and BE THE PERSON WHO THEY WANT TO BE. To make the choices that THEY WANT TO MAKE.

In order to work successfully and positively with someone who is PDA, we must choose to relinquish control ourselves.

Never Manage Issues with Restriction and Punishment

The stock standard school-based response to issues with children was always suspension, restriction from preferred activities and discussion of the issues which led to meltdowns and problems. These responses are extremely unhelpful and highly counter-productive for anyone with Autism and work AGAINST all the views and recommendations of specialists in this sector. Taking away movement opportunities, play times or breaks from a dysregulated child will only further dysregulate them and force them to mask (suppress) their needs further. Masking / suppression results in more explosive behaviour so this is never recommended.



Other Ways to Say NO & PDA Scripting

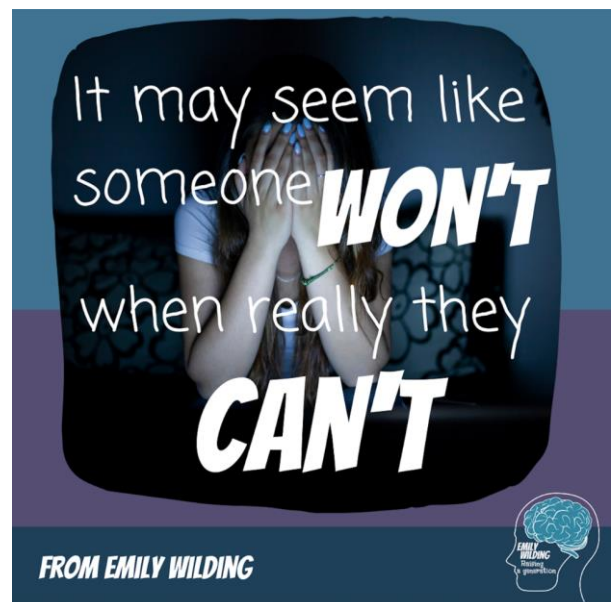
Language: Avoid no, avoid too much change language

There are so many ways to say 'no' without using the word. The word has often been used far too much with Autistic people and it's become toxic

Other ways to say "No" include:


- ✓ **Agree:** "Sure, that's up to you if you want to do that. Perhaps once we finish what we are doing if it suits you better?"
- ✓ **Offer a choice:** "Yeah, I understand that you want to do that, but remember you only have enough money for one of those things. Maybe do that, but don't purchase XYZ tomorrow – it's up to you."
- ✓ **Offer an alternative:** "Ahh you ate Fish and Chips yesterday with Jack remember, I thought you wanted some chicken and salad today?"

- ✓ **Distract/Redirect:** *“Holy Dooley, did you see [insert interesting thing] over there?”* Any kind of distraction may get the person out of the zone enough to not be as focused on the thing that they cannot do/have.
- ✓ **What would they like do about this?** If a person really likes the views of someone else, even a TV star or actor. You could ask what they might do about the decision.
- ✓ **Enlist help from an authority figure:** *“Let’s ask the doctor next week if that’s a good idea before we do it, just to make sure that we aren’t doing anything silly and making you feel sick or anything.”*
- ✓ **Agree that it’s difficult and sympathise:** *“I know, I hate that we can’t go down that road right now, how stupid that they blocked that off for no damn reason – how annoying, I reckon we tell them what we think next time.”*
- ✓ **Call on imagination:** *“Geez, there’s no traffic, how ridiculous. Imagine if there was a massive convoy of trucks though, how long do you think it would take a convoy of trucks to go down this main street?”*
- ✓ **Remind the person of a previous time that decision wasn’t so good:** *“Well, yeah I suppose you could eat that, but Geez, remember last time you did, and you were so sick we had to take you to hospital for 2 days? Do you really want to risk that again?”*




TYPES OF DEMAND AVOIDANCE

<p>ANXIETY DRIVEN</p> <p>All humans avoid things they are scared of and autistic people are more prone to this than neurotypical people.</p>	<p>EXECUTIVE FUNCTION</p> <p>People who experience executive function issues avoid tasks (or demands) that will be challenging for them with those issues.</p>
<p>FEAR OF FAILURE</p> <p>People who have low self-esteem may avoid demands if they feel that they will fail to avoid shame. Neurodivergent people are prone to this.</p>	<p>PATHOLOGICAL DEMAND AVOIDANCE</p> <p>Demand avoidance is only pathological when it is the demand itself, and not the activity, that causes distress and anxiety. PDAers can also experience the other types.</p>

FROM EMILY WILDING 

STAGES OF AVOIDANCE

<p>STAGE 1: LIGHT AVOIDANCE</p> <ul style="list-style-type: none"> • Distraction • Procrastination • Negotiation • Excuses • Masking 	<p>STAGE 2: STRONG AVOIDANCE</p> <ul style="list-style-type: none"> • Retreating into role/fantasy • Outrageous social behaviour • Incapacitating themselves • Ridiculous excuses • Outright refusal
<p>STAGE 3: MELT/SHUTDOWN</p> <ul style="list-style-type: none"> • Physical/emotional harm of self or others • Destruction of property • Extreme exhaustion • Uncontrollable crying • Depression / anxiety 	<p>A PDAer who is in a general state of anxiety may skip very quickly through the stages or may immediately melt/shut down at the slightest hint of demand.</p>

FROM EMILY WILDING 

WHEN KIDS SAY "NO!"

OUR INSTINCT	* OUR GOAL
<p>WE MODEL REVENGE "Then no TV for you!"</p>	<p>WE MODEL CURIOSITY "You don't want to. How come?"</p>
<p>WE MODEL GASLIGHTING "You're totally overreacting."</p>	<p>WE MODEL EMPATHY "I get that! Tell me more..."</p>
<p>WE MODEL INTIMIDATION "Ten, nine, eight..."</p>	<p>WE MODEL DIVERSITY "We've got different needs here."</p>
<p>WE MODEL CONDITIONAL LOVE "You're disappointing me."</p>	<p>WE MODEL CREATIVITY "We need ideas! How can this work?"</p>
<p>WE MODEL MANIPULATION "How about a cookie after?"</p>	<p>WE MODEL SELF-REGULATION "I'm going to take some breaths."</p>
<p>WE MODEL SHAMING "Go to your room!"</p>	<p>WE MODEL VALIDATION "You REALLY don't want to!"</p>
<p>WE MODEL DOMINATION "Then I have to MAKE you."</p>	<p>WE MODEL BOUNDARY-SETTING "I can't let you hit me, honey."</p>
<p>WE MODEL JUDGEMENT "You're being so selfish."</p>	<p>WE MODEL RESPECT "Totally. Can I tell you why?"</p>

RAISE & RESIST! #jointheupbringing @upbringing.co WWW.UPBRINGING.CO

Help us move the change to non-ABA strategies by adopting brain-based and sensory based integration interventions.
Join FB group "The OTHER Way" to find the community pushing this movement.

[The OTHER way \(public group\) | Facebook](#) *There are no copyright restrictions on this work and you're welcome to share it.