DivergAntz Collective

Instinct

for when the majority get it wrong

UNSOLVED PROBLEMS

AND

STRATEGIES FOR SUPPORT

CONTENTS

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The OTHER way (public group) | Facebook

The information across the following pages is designed to support a range of participants with varying needs and complexities.

Not all of the following strategies are designed for everyone. Some of the strategies in the following pages are designed for those who are Autistic and/or ADHD and some are designed for Neurotypical children or adults who are living with complexities regarding their communication, sensory processing, history of trauma or interactional complexities with others.

Please ensure you seek specialist support regarding any strategies used with children and adults as not all strategies will suit all children and adults.

Feel free to reach out to clinicians from Instinct Au for support to determine which strategies might be suitable for any loves ones you are hoping to provide support to.

Thanks, and we hope this helps, feel free to share it around.

Tara Kent and the Instinct Au and DivergAntz Collective teams ☺

Pathological Demand Avoidance (PDA) and Autistic Demand Avoidance

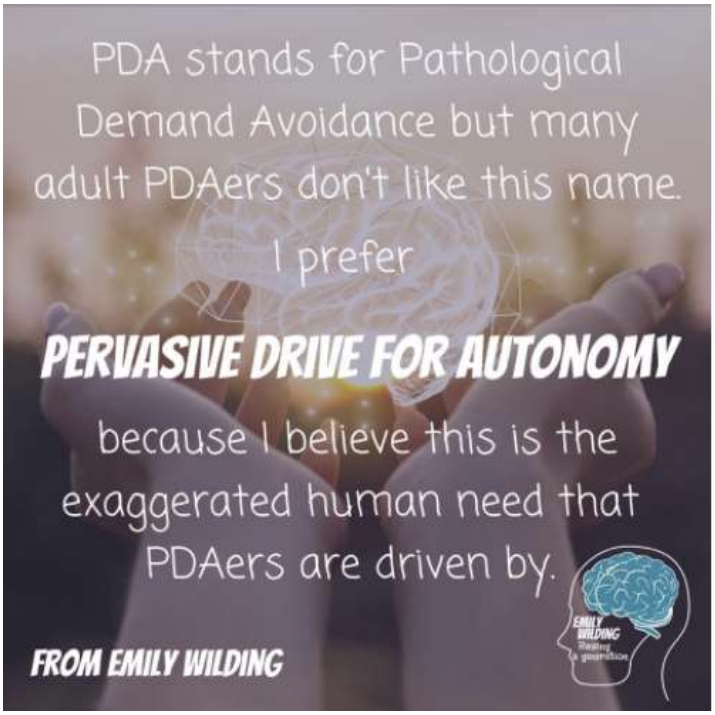
Pathological Demand Avoidance (PDA) and Autistic Demand Avoidance are terms which relate to an uncontrollable and unintentional compulsion to avoid demands placed upon you and to refuse to comply with (even simple) requests. People who have what we regard as having a "strong PDA profile" often appear 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 Autistic 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.

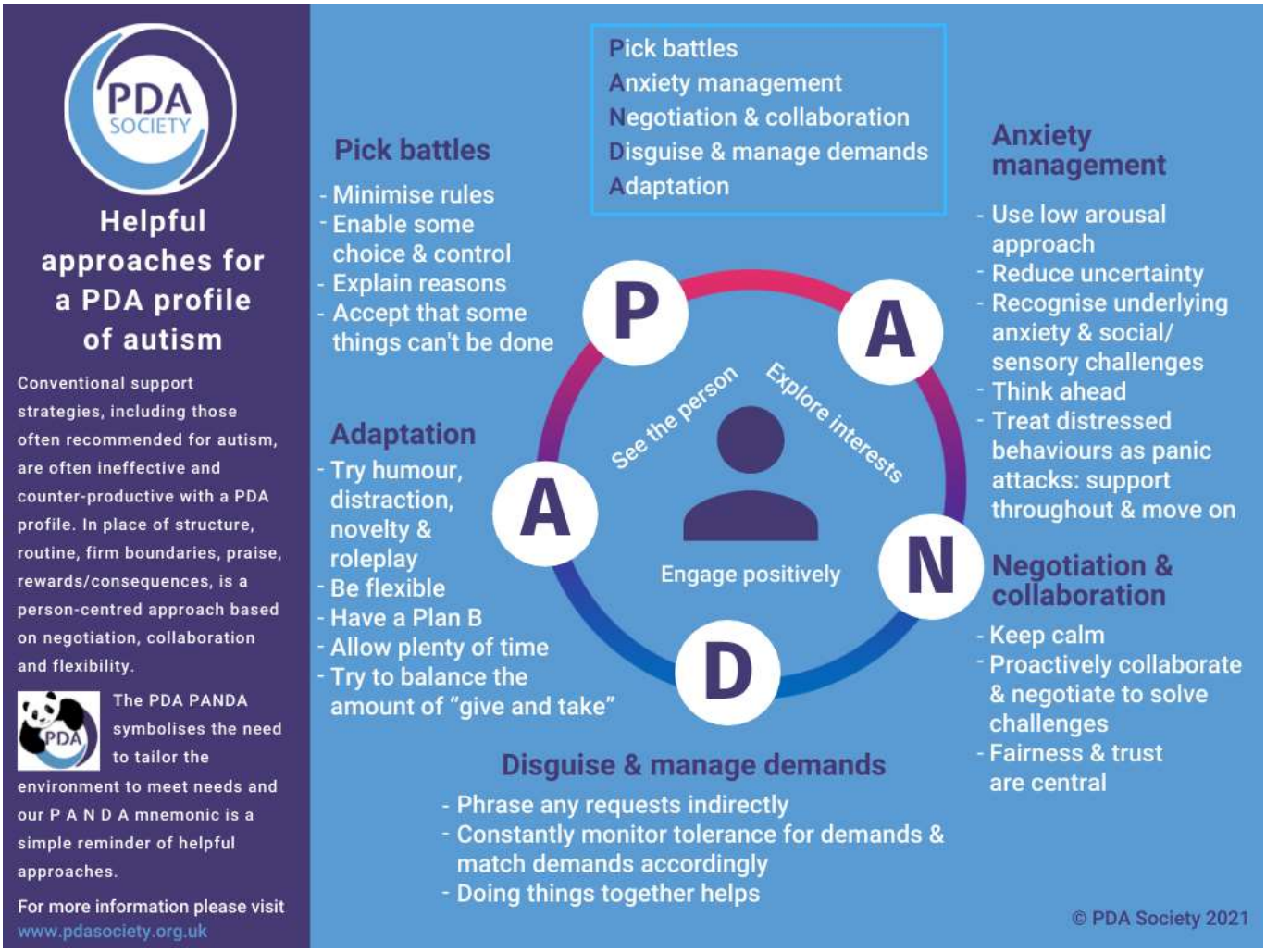
Some of the most difficult things for anyone with a PDA profile are:

- 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.



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

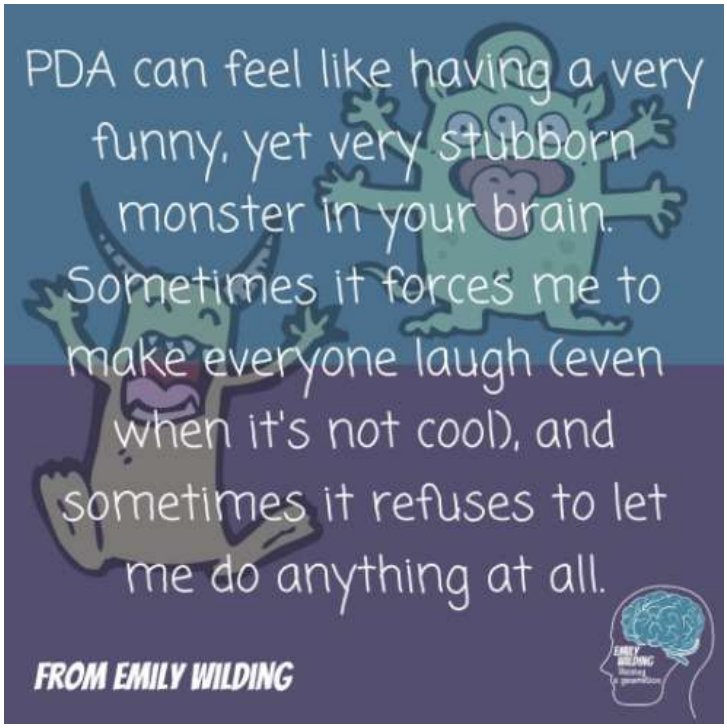
need assistance to cognitively transition to a new environment or task. This will be explained further later on in this information sheet.

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 to 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 picture above 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 (not 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 in 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.

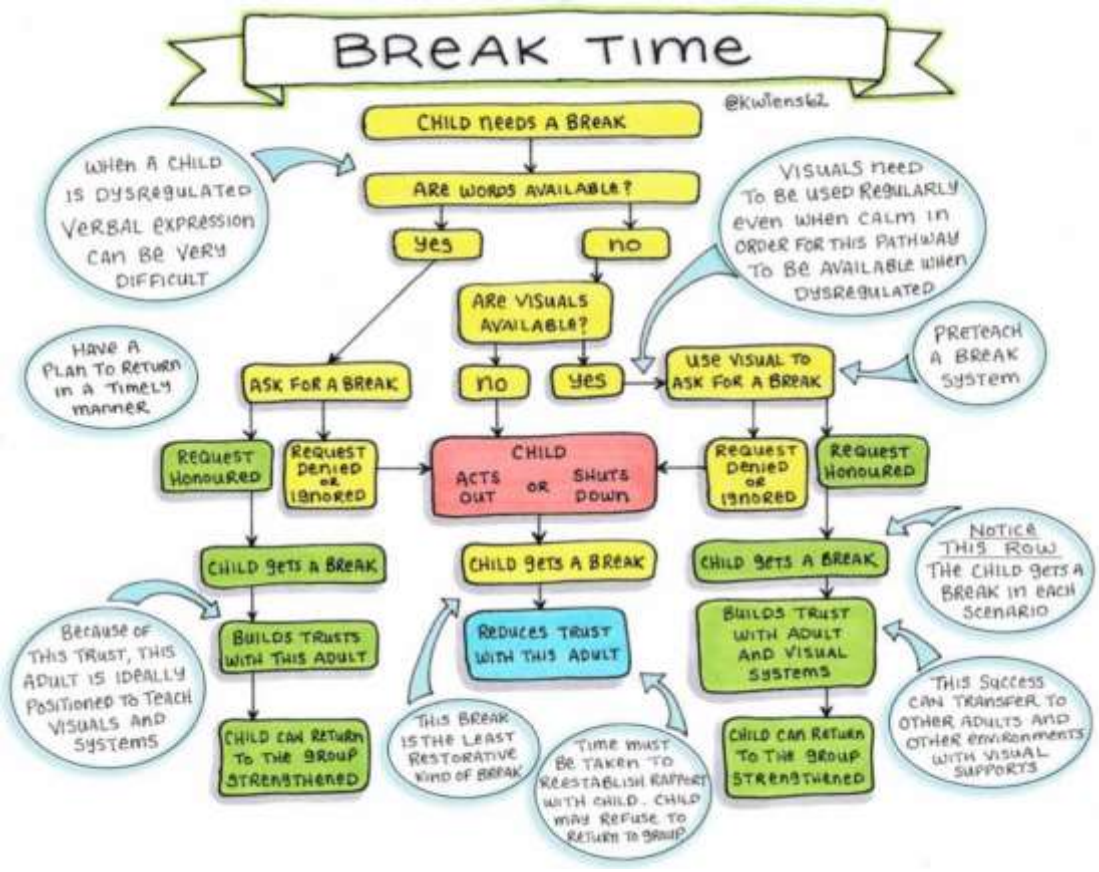
A hard thing for many to understand these days is:

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

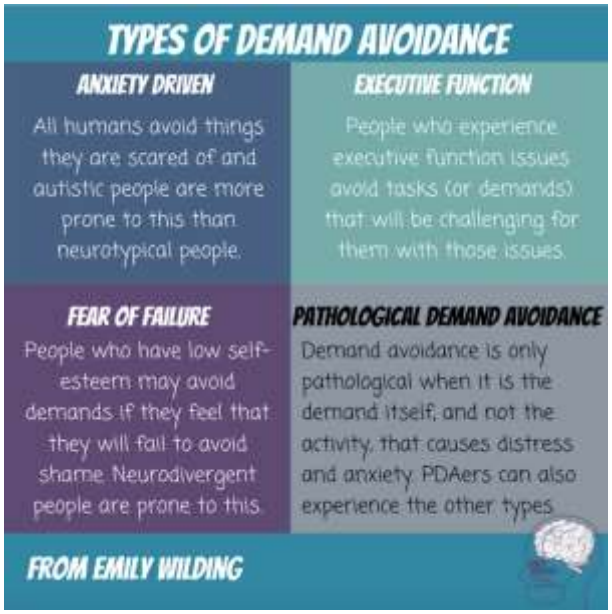
Language: <u>Avoid 'No', avoid too much change language</u>

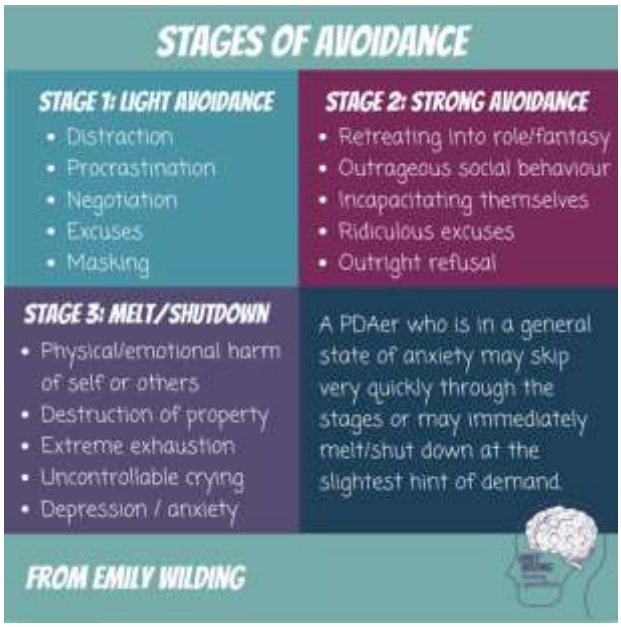
There are so many ways to say 'no' without using the word. The word has often been used far too much with Autistic people and it's become toxic

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' 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?"*





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Sensory Input and Sensory Processing Disorder

Overwhelmed by sensory experiences

Everyone has a sensory profile. Everyone has differing sensory needs. A sensory processing disorder is when a person's sensory needs cannot be met the way they normally live their life, and they need to do extra things and/or help from other people to meet their needs.

Our senses include the following 8, not 5 like we were originally taught.

Our senses include:

(1) Sight and Vision / Visual Input.

(2) Hearing / Noise / Auditory Input.

(3) Touch / External Feeling.

(4) Taste.

(5) Smell.

(6) Vestibular Input / Movement.

(7) Proprioception / feelings, input and sensations from your joints, muscles and connective tissues.

(8) Interoception / Inside Feelings and Emotions and Emotional Input.

Feeling Regulated and Safe

If our sensory needs are not met properly, we don't feel regulated (comfortable / normal) and safe. Feeling regulated is important as without regulation, the person could have a variety of experiences and feelings which mean they can't function normally, may not be able

to manage their actions, cannot concentrate and don't have control over their body. Regulation is about having control over your body and its actions, its movements, its responses, and the way it takes in input. An unregulated person may feel scared, feel starved, feel depressed and overwhelmingly sad or distressed, feel needy, feel fidgety and awkward, feel unsettled and constantly unhappy. With some sensory processing disorders, some people can experience psychotic type symptoms when they are not regulated. This can appear like hearing voices, feeling suicidal[1], feeling like you're trapped and cannot function or exist, feeling sick and unable to talk or move, or feeling totally helpless. Getting regulated is essential for people as this enables them to feel like their body is happy and they can function. Being dysregulated is torture for some people and has been described as overwhelming physical and emotional pain, devastation, inability to go on and totally consuming of all other senses and focus.

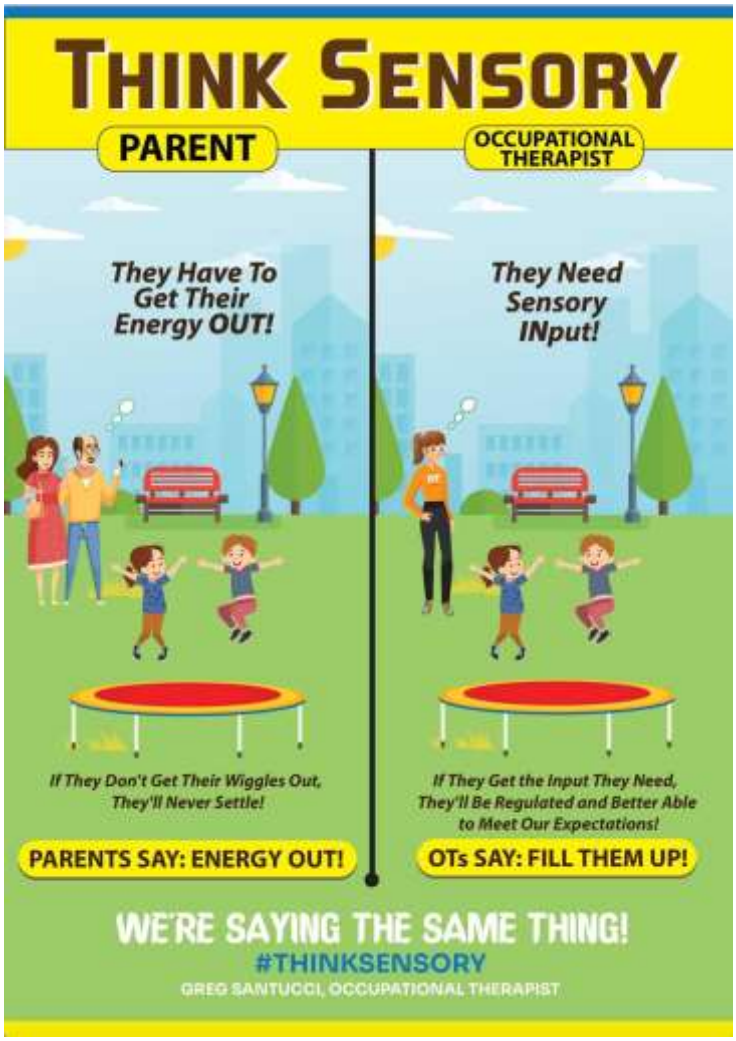
With some sensory processing disorders, the person may not be able to talk or hear when they are dysregulated due to another sensory issue (e.g., if the person cannot manage the light, their headache and internal pain may become so severe that they cannot even talk

[1] https://www.sciencedirect.com/science/article/pii/S0006899313012134?via%3Dihub

or communicate while this overwhelming sensory experience is happening).

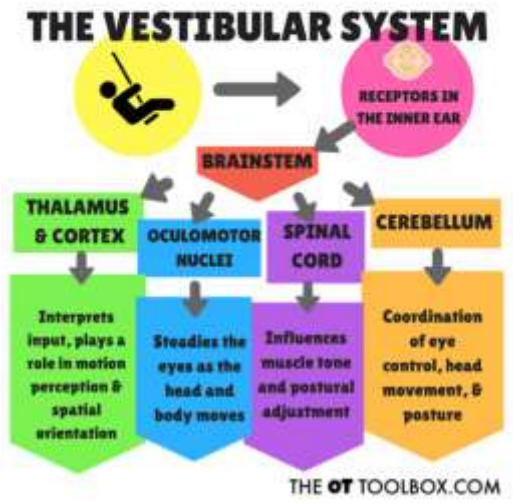
Many people don't understand vestibular, proprioceptive or interoceptive sensory input. To help with this understanding, some further information is provided below.

Vestibular Sensory Input and Avoidance



This type of sensory input is based on movement. *"The vestibular system is a sensory system that is responsible for providing our brain with information about motion, head position, and spatial orientation; it also is involved with motor functions that allow us to keep our balance, stabilize our head and body during movement, and maintain posture. Thus, the vestibular system is essential for normal movement and equilibrium."*[2] People who have a high sensory-seeking profile will be people who need high levels of vestibular movement to feel regulated. These might be people who need to do a lot of exercise / sports to settle and who cannot sleep and feel 'twitchy' if they haven't moved around a lot. As children, people who need a lot of vestibular movement, are those who cannot sit in class without movement for lengthy periods of time and who struggle to listen to people if they have been still for too long.

[2] https://www.neuroscientificallychallenged.com/blog/know-your-brain-vestibular-system



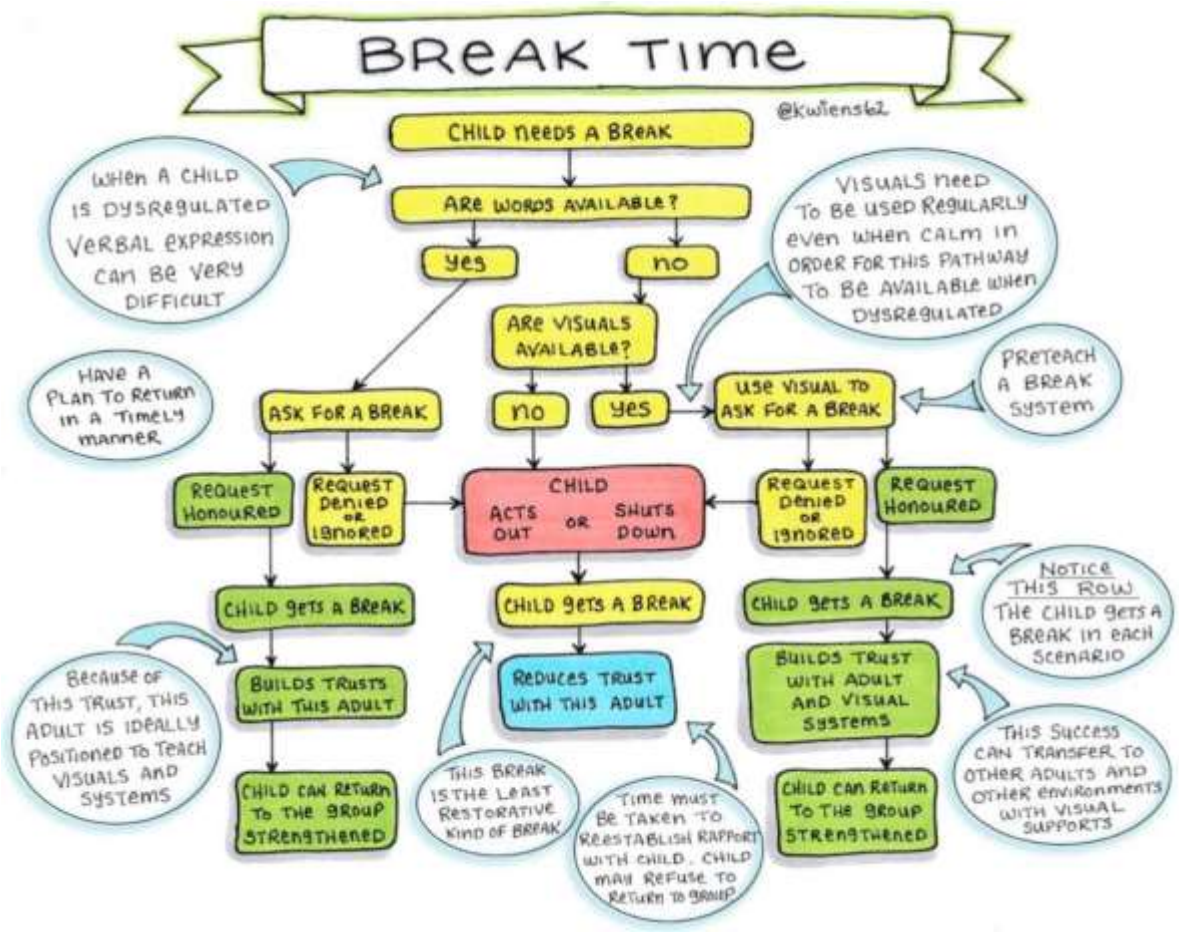
"The vestibular system is comprised of several structures and tracts, but the main components of the system are found in the inner ear in a system of interconnected compartments called the vestibular labyrinth. The vestibular labyrinth is made up of the semi-circular canals and the otolith organs (all discussed below), and contains receptors for vestibular sensations. These receptors send vestibular information via the vestibulocochlear nerve to the cerebellum and to nuclei in the brainstem called the vestibular nuclei. The vestibular nuclei then pass the information on to a variety of targets, ranging from the muscles of the eye to the cerebral cortex."[3]

Reports indicate that children who need high levels of movement and don't get it can show signs of dysregulation which can appear like severe mental health distress. There have been reported incidents of children and adults in hospital, with symptoms of psychosis, hearing voices and experiencing trauma because of the effect on the brain from not gaining sufficient vestibular input.

Breaks, a necessary and natural human right.

The following infogram shows the importance of having a break and debunks any ideology that this isn't a necessary right. Especially children who often require vestibular sensory input (movement) to help them be regulated require regular breaks, even more than what's been allocated.

[3] https://www.neuroscientificallychallenged.com/blog/know-your-brain-vestibular-system



Proprioceptive Sensory Input and Avoidance

This type of sensory input is based on the relationship between your body and the world. This includes pressure and tightness of feelings on your body.

"The proprioceptive system is located in our muscles and joints. It provides us with a sense of body awareness and detects/controls force and pressure. The proprioceptive system also has an important regulatory role in sensory processing as proprioceptive input can assist in controlling responses to sensory stimuli.
Proprioceptive input can be very calming for those who are easily overwhelmed by sensory stimulation.
Proprioceptive input can be alerting for those who need increased sensory stimulation to facilitate attention and learning."[4]

[4] https://sensory-processing.middletownautism.com/sensory-strategies/strategies-according-to-sense/proprioceptive/

People who crave or sense the experience of proprioceptive sensory input are likely to be people who:

- Want to bite and chew things a lot (craving input).
- Chewing very slowly and drinking cautiously (sensing input).
- Love tight spaces, being squeezed, tight fitting clothes and heavy blankets (craving input).
- Walking on tiptoes (craving input) and/or focused and concentrated walking (sensing input).
- Throwing themselves heavily on the floor, or against the wall or other people (craving input).
- Loves to sit with legs or arms all tucked up and looped over, might prefer to sit on the ground (craving input).
- Holds things (such as pencils) with excessive grip and pressure. Might write heavily on paper (craving input).
- Hits head or body (craving input).
- Swallow things, or insert things into places, they shouldn't (craving input).

People who don't like (avoid), or have little awareness (bystander) of proprioceptive sensory input are likely to be people who:

- Struggle going up and down stairs (due to spatial awareness).
- Don't like people touching them or sitting too close to them.
- Are not very physically capable, have joint mobility issues, struggle with things like Ehlers Danlos Syndrome (EDS), have reduced or poor joint flexibility.
- Get dizzy easily and not cope with changes in light when connected to movement.

Exercises to help people struggling with proprioceptive sensory input include:

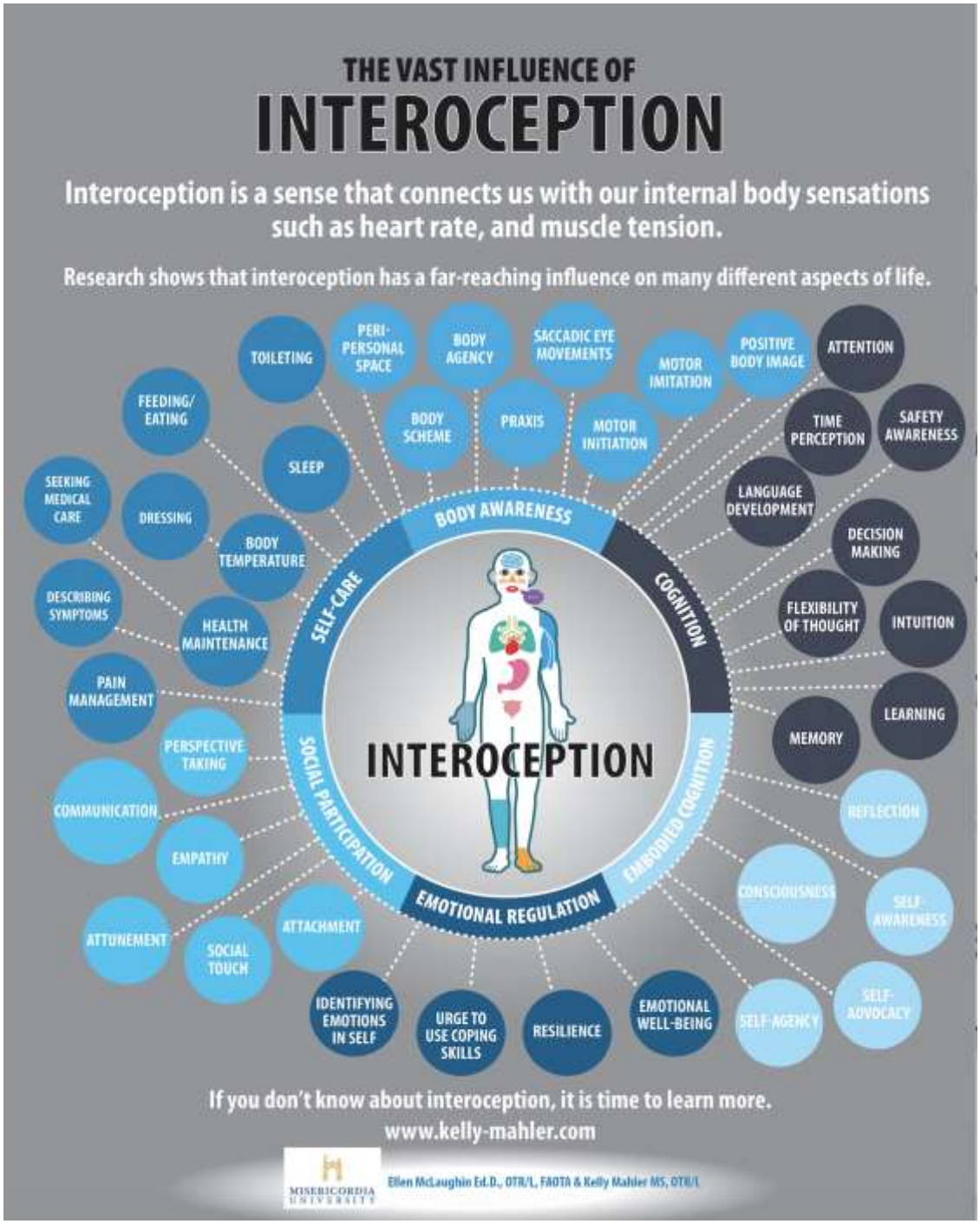
- Chewellry (chewy necklaces etc).
- Pushing and pulling on hands and clapping.
- Chair push ups, squeezing rubber bands around legs of chair.
- Bouncing with balls, including seated balls and exercise ball.
- Tug of war.
- Gymnastics style activities such as handstands, cartwheels, star jumps, gym equipment.

- Space hoppers, lying on stomach and weight-bearing using arms.

There are lots of equipment to help people who need proprioceptive sensory input. This can include balance beams, tight bands for around their legs, space hopper and exercise balls, therapy pods, tight sheets for around their bed, body socks and other compression-based items.

Interoceptive Sensory Input and Avoidance

This type of sensory input is based on feelings inside your body. Have a look at the image below, by Kelly Mahler. This shows the range of matters that Interoceptive input includes.



Interoceptive sensory input is one of the hardest to assess and explain as it's all about things happening inside the body. Interoception relates to **feelings of** [5]:

Hunger	Fullness	Thirst	Pain	Illness
Body Temperature	Sleepiness	Need to use the toilet	Anger	Distraction
Focus	Calmness	Boredom	Relaxation	Sadness

Just like any other sensory modality, we can experience interoceptive input in a variety of diverse ways. Some of us may not be able to feel things happening in our body and might struggle to know when we are about to urinate, or not feel pain in our body. Some of us are not able to say when we are thirsty or hungry as we don't feel those feelings, or if we do, we don't know we are feeling them.

Examples of people with **amplified interoceptive sensory input** (e.g., People who experience this input at a much greater extent than others). These people may or may not also be cravers and sensors of this input.

- People who get very upset by feelings of hurt or sadness, much more than others would in their situation.
- People who can control their bladder or bowels to heightened extents.
- People who feel their bowel or bladder to a much greater extent. For avoiders (who don't like the input) it's possible that a person may experience the input they hate in a heightened manner.
- People who experience pain to a much greater level than their peers.
- People who cannot manage changes in temperature and may hate having showers or get irritated in changing weather.

Examples of people with **bystander interoceptive sensory input** (e.g., People who experience this input at a much lesser extent than others).

- People who don't learn when they are needing the toilet and might need to wear incontinence aides for a long time.

[5] Kelly Mahler, Interoception Daily Activity List

- People who cannot tell when they are in pain and show they don't experience (feel) it much at all.
- People who wear jumpers in summer and/or can sleep outside in the cold without feeling the low temperatures.
- People who eat endless amounts and don't feel full, and/or those who don't eat for ages as they don't feel hungry.

Sensory Sensors and Avoiders – What It Can Look Like

Sensors and Avoiders are people who need to manage and limit the sensory input they receive due to small amounts being overwhelming to them. These people sense (feel / experience) certain things ***more*** *than others would. Examples of such people include:*

- Someone who hates noise and must wear noise cancelling headphones (avoider of noise input).
- Someone who hates too much movement and becomes easily overwhelmed with physical activity (avoider of vestibular input).
- Someone who cannot cope with the feelings in their joints, muscles, and connective tissues and/or experience pain with movement and struggles (avoider of proprioceptive input).
- Someone who cannot stand lots of light and gets headaches easily in well-lit environments (avoider of visual input).
- Someone who cannot manage strong emotions and feelings and can become very overwhelmed, distressed, possibly depressed easily, and feel disturbed from feelings (avoider of interoceptive input).
- Someone who cannot manage feelings like being sick, having a headache, having period pain, having neurological processing issues subsequent to epilepsy, feelings of

moving their bowels to defecate, feelings of food being swallowed and processed by the body (avoider of proprioceptive / interoceptive sensory input).

- Someone who cannot cope with feelings of anxiety or if their tummy feels tight when they are sick or worried (avoider of interoceptive sensory input).
- Someone who cannot stand certain fabrics on their body and cannot touch certain textures (avoider of certain touch).
- Someone who struggles with visual changes, such as movement and gets very dizzy in situations where there is lots of movement (avoider of visual input and possible avoider of vestibular input).
- [6]Someone who can't stand the taste of certain foods. In some situations, this can be very serious and very specific. In extreme situations, this may be diagnosed as Avoidant Restrictive Food Intake Disorder (ARFID) which now has its own DSM V diagnosis due it's severity and increasing commonality (avoider of certain tastes).

Avoidant Restrictive Food Intake Disorder (ARFID) is a new diagnosis in the DSM-5, and was previously referred to as "Selective Eating Disorder." ARFID is similar to anorexia in that both disorders involve limitations in the amount and/or types of food consumed, but unlike anorexia, ARFID does not involve any distress about body shape or size, or fears of fatness.

Although many children go through phases of picky or selective eating, a person with ARFID does not consume enough calories to grow and develop properly and, in adults, to maintain basic body function. In children, this results in stalled weight gain and vertical growth; in adults, this results in weight loss. ARFID can also result in problems at school or work, due to difficulties eating with others and extended times needed to eat.

Sensory Sensors and Avoiders – What It Can Look Like When They Need Help

Sensory sensors and Avoiders need to avoid the sensory input that they don't like. If they can't avoid this input, it can be very distressing and sometimes excruciating and painful for them.

[6] https://www.nationaleatingdisorders.org/learn/by-eating-disorder/arfid

- Someone screaming, having a meltdown or self-harming because the sensory input they are receiving is so overwhelming that it's painful for them.
- Someone vomiting, dry reaching, gagging, and spitting out food from their mouth.
- Someone holding their ears, covering their eyes, covering their mouth or any other part of their face or body to stop the sensory input, or at least reduce it.
- Someone constantly taking off their clothes or shoes, refusing to wear certain clothing, shoes, or socks, or refusing to touch or feel certain surfaces.
- Someone tripping or falling over.
- Someone unable to talk to you, or situational mutism in situations when they feel overloaded from sensory input.
- Someone who talks extremely fast, or must jump and move as they talk, because they can't stand the way their body feels at certain times or in certain temperatures.
- Someone who cannot go swimming in certain temperature water or who screams in the shower if the water is too cold, or just due to the water touching their body.
- Someone who becomes extremely distressed at emotional situations (including friendships and relationships) and may want to hurt themselves or self-harm when things become overwhelming, and they don't have the interoceptive skills to manage the feelings safely.
- Someone screaming so loud and hitting themselves to create their own sensory experience (that they can manage, and which helps them regulate) to avoid sensory input they can't manage (such as internal feelings).
- Someone hiding from people and crying when they are in social environments because the noise is so overwhelming that it becomes painful. This can also present as a heightened focus on just the noise of a fan, or an air conditioning unit working in the background that most others don't even hear.
- Someone who gets extremely distressed around the time of, or during going to the toilet as they cannot stand the feeling of the bowel movement through their body.
- Someone who will not spit something out of their mouth, nor swallow it as it doesn't feel right in their mouth.

Sensory Seekers

Seekers are people who crave and need more sensory input than others. This need can be desperate and urgent, and many people don't even realise they have these needs. These are people who feel / experience sensory input less than other people would and need help topping up their sensory bank to feel regulated and safe. Examples of such people include:

- Someone who likes extra chilli and spice in their food (seeker of taste).
- Someone who loves lights and the sun and loves to stare at lights or colours (seeker of visual sensory input).
- Someone who constantly plays on their iPad, computer, device and can spend hours just receiving the same sensory input (seeker of visual sensory input).
- Someone who loves movement and needs additional movement and activity (seeker of vestibular sensory input).
- Someone who chews everything, or walks around, licking surfaces of things (seeker of taste sensory input).
- Someone who wants to touch everything all the time (proprioceptive or tactile sensory seeker).
- Someone who loves feelings and emotions and craves emotional situations (seeker of interoceptive sensory input).
- Someone who loves making noise and loves noisy environments and makes lots of noises themselves, this could be by vocal scripting (which can also serve other purposes for the person) and by other verbalisations or movements with their body which create noise (seeker of auditory input).
- Someone who puts lots of salt or lots of flavouring on their food to make it stronger in taste and/or might like strong lollies like Warheads (seeker of taste sensory input).
- Someone who enjoys the feelings their joints, muscles and connective tissues make, and likes to move in different ways and feel additional input (seeker of proprioceptive sensory input).

Sensory Seekers – What It Can Look Like When They Need Help

Sensory seekers need to consistently receive the sensory input that they need and crave. If they can't receive this input, they often feel awful and can experience sickness, pain and

feelings of total hopelessness and loss from not having their needs met. Examples can include the following:

- Someone who goes up to people they don't know and smells their clothes or hair.
- Someone who puts lots of things in their mouth, even those that aren't meant to be tasted or eaten. Sometimes the person might spit them out again, sometimes they might be swallowed.
- Someone whose joints and bones feel sore and achy when they don't use and move them and move around a lot.
- Someone who needs the constant visual sensory input they get from their iPad, computer games, devices, television and then becomes depressed, self-harming and unmanageable when they are asked to reduce the time, they spend on the devices that provide them this sensory input.
- Someone who becomes depressed, shows signs of psychosis, or hear voices[7], who is not receiving sufficient vestibular sensory input. Vestibular input is directly linked to neurological feelings of safety and wellness and has a strong link with mental health.
- Someone who is morbidly depressed, feeling unloved by everyone and thinks no-one wants to be around them.
- Someone who takes things off people, tips out drinks, throws items around erratically.
- Someone who appears as if they have poor impulse control, e.g., who might run off suddenly to touch something, or who might quickly shove something on their face or in their eye, without thinking about danger or exercising any caution.
- Erratic, sudden and unpredictable movements are very likely for a sensory seeker to demonstrate if their needs are not being met. This can look like they are demonstrating unpredictable and irrational behaviour, when really, they are craving a certain type of sensory input and don't know how to regulate themselves.
- Rubbing genitals in public, or pushing genitals against tables, chairs or into other people. This is particularly common in adolescent boys with a heightened sensory profile. This behaviour can be very controversial because many believe any behaviour related to genitals is sexually driven. In many situations, those who seek sensory input

[7] https://www.sciencedirect.com/science/article/pii/S0006899313012134

may just be trying to regulate themselves by acquiring specific sensory input and/or needing touch or movement in a certain way.

Masking

In the Loop About Neurodiversity
16 April 2019 ·

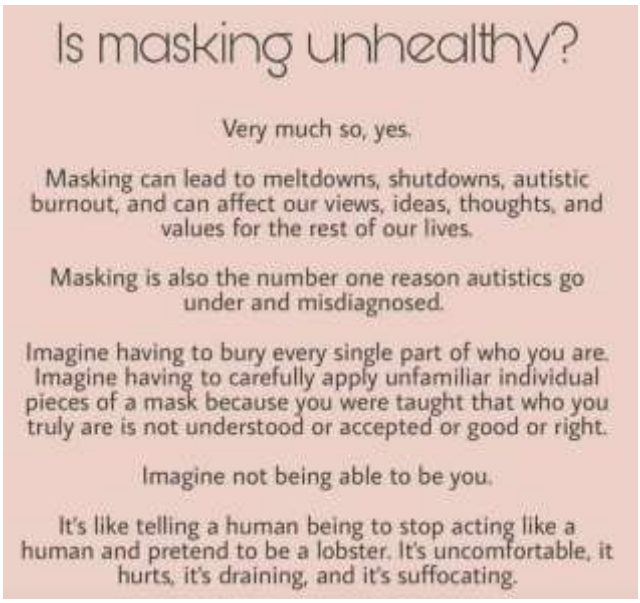
Social masking is when autistic people attempt to appear neurotypical by hiding their autism such as suppressing stims, forcing eye contact, and meeting other social norms, even if it makes them feel uncomfortable. While social masking can help in social situations, autistic people would prefer not to resort to social masking, as it can cause anxiety, stress, exhaustion, and even psychological harm. Someone who is socially masking may be smiling or appear to be fine, but may be screaming internally or in distress from having to suppress who they are. Let's create a culture of autism acceptance so autistic people can feel free to take their mask off and be themselves in social situations. #MemeMonday #TaketheMaskOff #EmbraceNeurodiversity #AutismAcceptance

Images in pink backgrounds are from @myautisticsoul

It's likely that school/work and other social situations will be exhausting for Autistic people, due to the social requirement by family and the world to fit in. Masking is when an Autistic person puts on a socially appropriate face and attitude to get through a situation. This might mean he or she has to suppress their urges to scream, hit or push others as they know they might get in trouble from teachers, parents or peers if they do these things. As much as it's not ok for anyone to push or hurt others, suppressing urges such as these (masking) can also be problematic and lead a person to have difficulties later in life when they force themself to mask in more and more situations. It's important that the person has the opportunity for loud

and silly play or interaction to enable other needs they have, such as those regarding feel and noise and physical energy.

Children and adults who mask in order to manage neurotypical needs/demands and/or social pressure will often have meltdowns as a result of the masking. Masking is exhausting and can lead to feelings of a need to sleep for hours (for some) or explosive meltdown energy (for others). It's common to see an increase in meltdowns after a child has recommenced the school year (example) or started attending a program or started working as they are forced to suppress their urges to manage the environment.



The best way to manage meltdown behaviour is to explore possible times that the person may be being forced to mask and try to reduce the necessity for them to mask.

Ways to tell that someone is masking include:

- Sensory, motivational or other assessments which have vastly different results at home and at school / work / day service. This is likely to mean that the person is suppressing their urges at one of these environments. This is why you cannot see the same sensory need and/or function of behaviour.

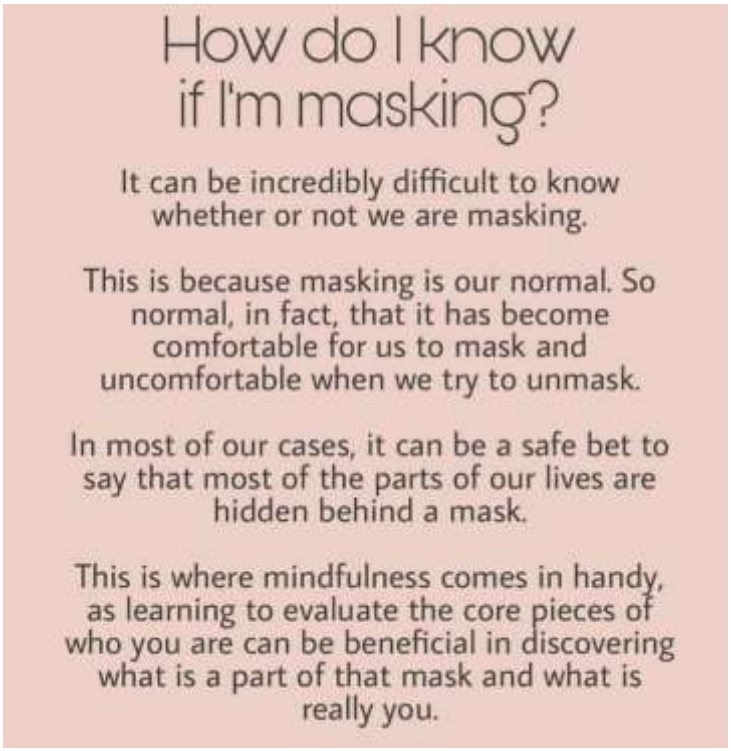
- Increased meltdowns after commencing a school year / new job / socialising.

- Increased anxiety around socialising.
- Scripting in social situations (e.g., a script for the shop attendant, a script for the chemist, a script for the phone call). Scripting is often a way of masking, a way of managing situations using practiced strategies.
- Lots of apologising, or changing what the person said (e.g., correcting themselves).
- Fidgeting in a way that makes it look like the person is suppressing their stims.
- The person explains the process they had to follow to 'force' themselves to turn up (this can indicate they don't want to be there and are masking to endure the situation).

Why mask?

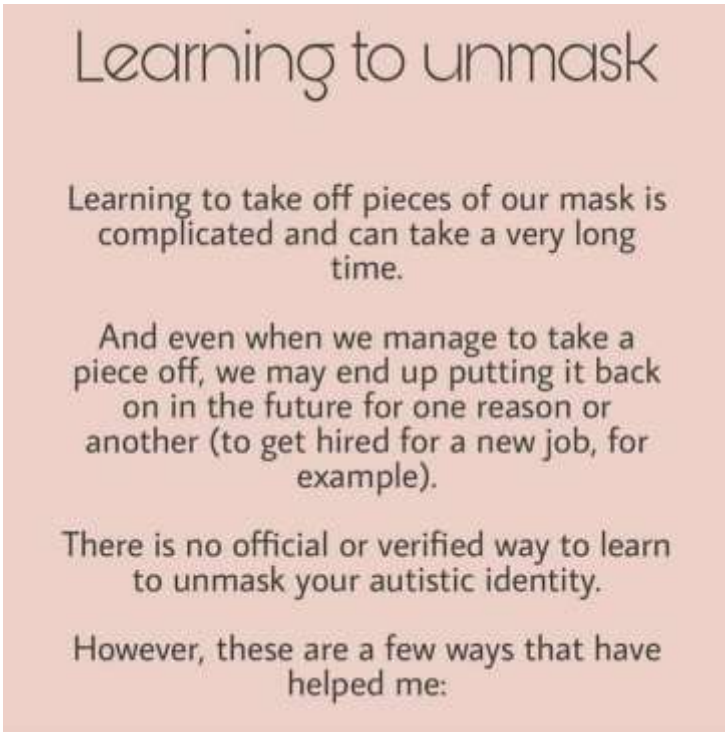
Society struggles to understand many neurodiverse accommodations such as stims, fidgets, noises people like to make to feel comfortable. Autistic people can get awkward looks from people, not be invited to places, have people complain about noises they might be making to make themselves feel comfortable be asked to stop doing things that others might find annoying.

Further to this, much of autistic communication is quite purposeful and can come off as blunt and to some, a bit rude. Autistic communication is often provided without the 'bells and whistles' that neurotypical people apply, including smiles, pauses for feedback, gestures to keep things appearing friendly, subtle micro-communication prompts like touch and grins to help everyone feel happy. Most autistic communication is designed to communicate a message clearly, with purpose and doesn't include these neurotypical nuances.



Sometimes it's hard for some people to even know if they are masking as they can become so used to doing it to fit in and survive. However, masking is quite dangerous and can lead to severe depression, anxiety and burnout.

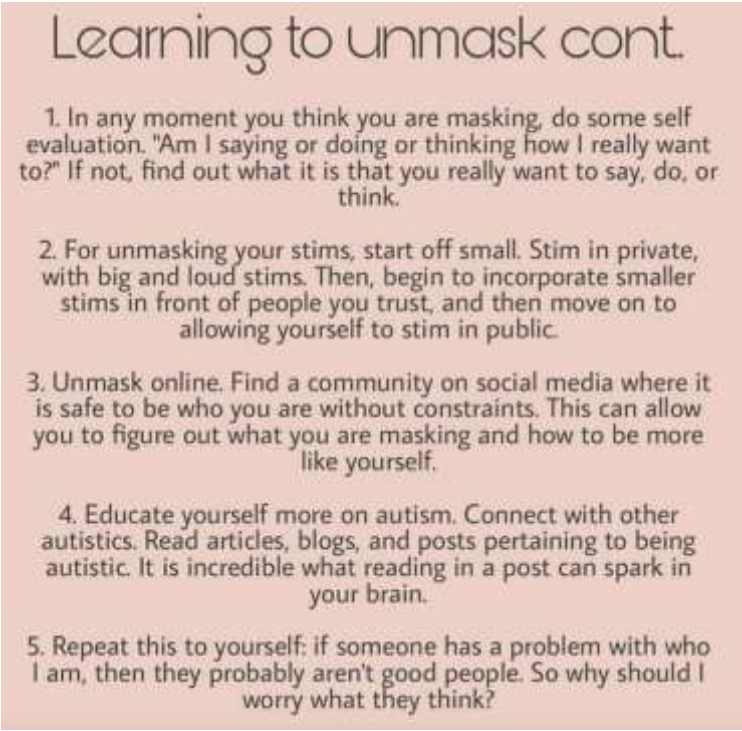
Masking is very common in day service, social environments and school. Sometimes the person does it to fit in, sometimes it's forced of them due to set expectations and in some situations (mostly schools) the child is told things like "look at me when I'm speaking to you", "shake hands when you meet someone", "make eye contact", "say things in a nice way, you're too blunt and rude". All of these comments are effectively telling the person that who they are isn't right and they need to change. This leads to masking. The person doesn't need to change, the expectations of them is what needs to change.



Stopping the need to mask / unmasking

It's important to identify masking and to help people to stop needing to use masks to manage life and situations. The way to stop the need for masks is to provide more freedom of expression with less judgement of the way a person needs to accommodate and regulate themselves. Sometimes people need to touch and smell things and sometimes people communicate a little more bluntly that others are used to. It's better to work with others on

why they perceive certain communication styles to be so blunt, rather than trying to force people to communicate unnaturally and subsequently need to mask.



Some strategies might include:

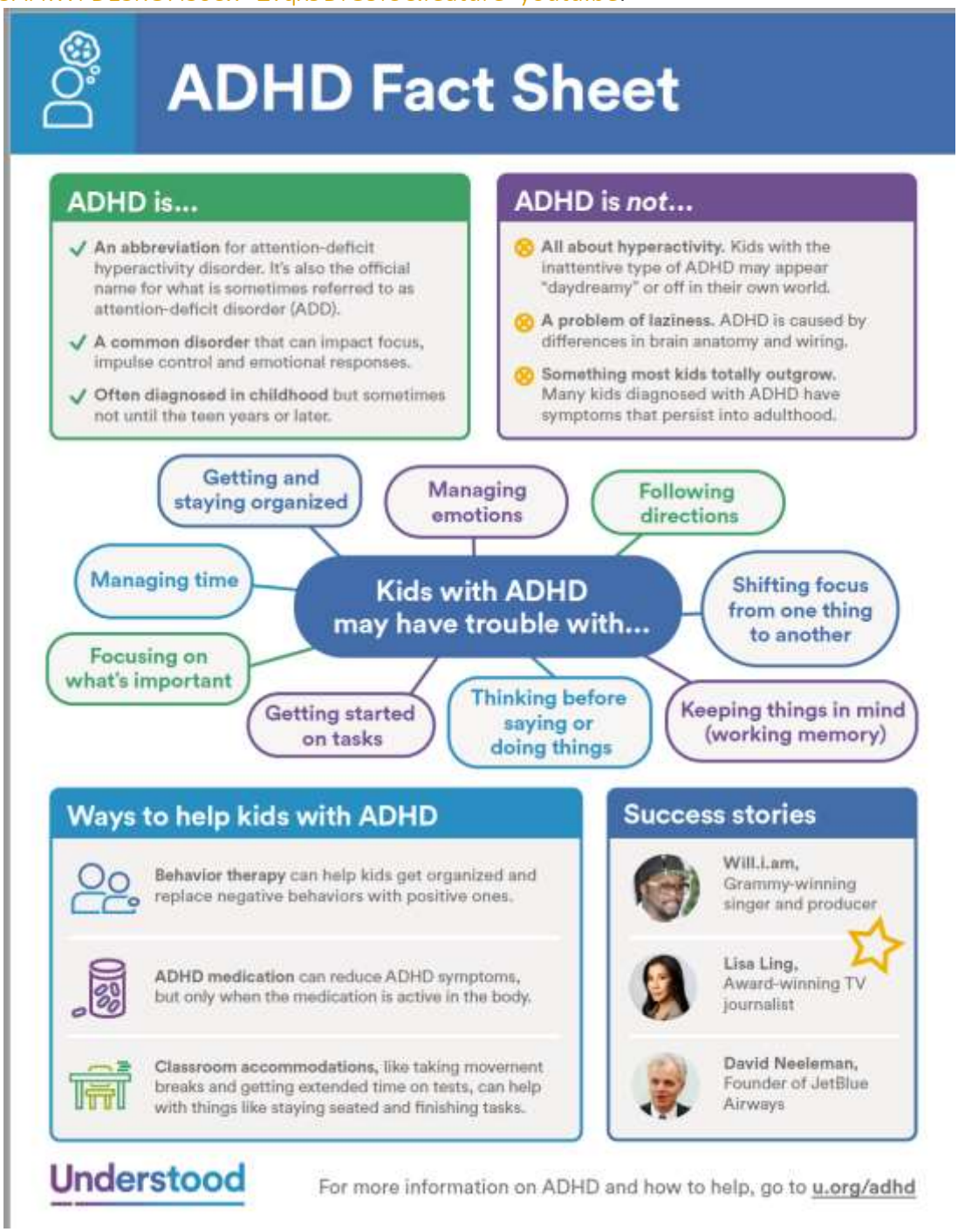
- If you're with a child, make sure you provide lots of opportunities for silly and outrageous playing. Autistic children need the opportunity to squeal and yell and sing at the top of their voices and throw things and bounce excitedly. It's important that there are regularly accessible opportunities for this to happen. Unrestricted expression of energy and excitement is very important. This might be loud and very busy, but it is very necessary to help children regulate.
- Try to help others to understand that we don't all have to act and talk the same. Blunt communication isn't necessarily rude in intention, regardless of how the person receiving it perceives it.

Watch for signs of masking. If someone is masking, they have an unsolved problem and need help. Ignoring masking can lead to the person experiencing meltdowns and burnout.

Attention Deficit Hyperactivity Disorder (ADHD)

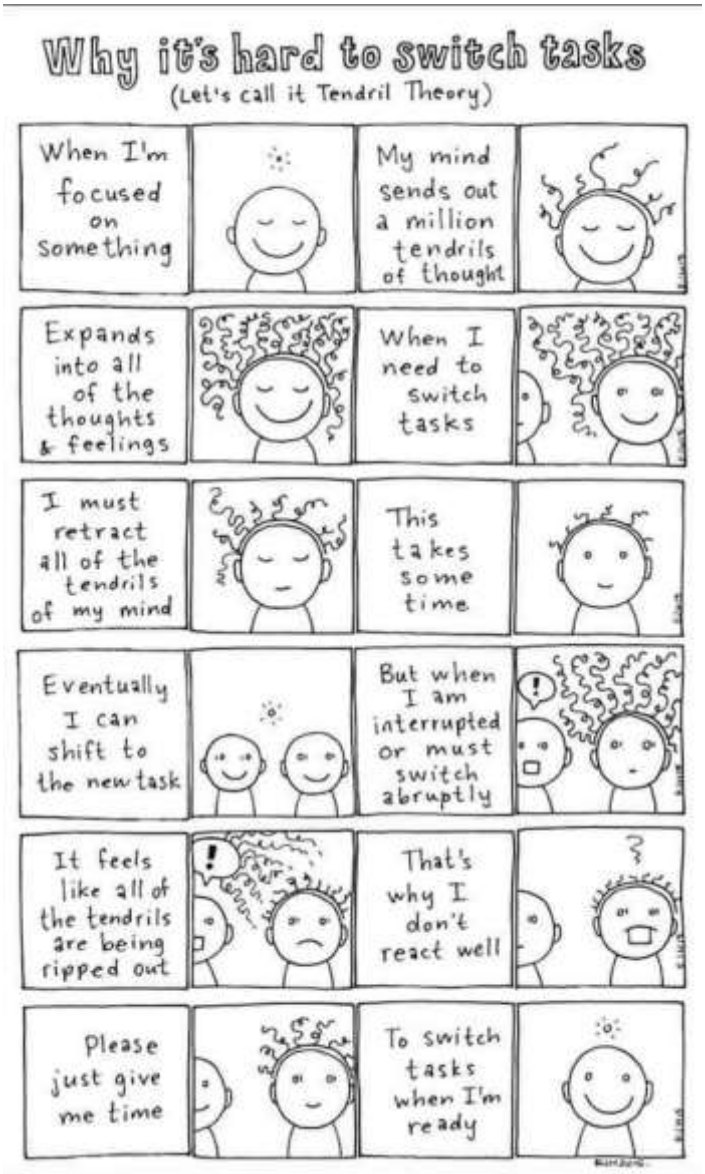
Please start this training by watching and listening to this wonderful song which provides an opening explanation of how ADHD affects the brain and the processing of information:

https://m.youtube.com/watch?fbclid=IwAR2CUB5iy0wqzOw2xpGhTLYozpLISyv2eeo6M2Qvy2qb5AFkWFDESKG7iS0&v=Zvqx9DfG9lU&feature=youtu.be.



What is ADHD?

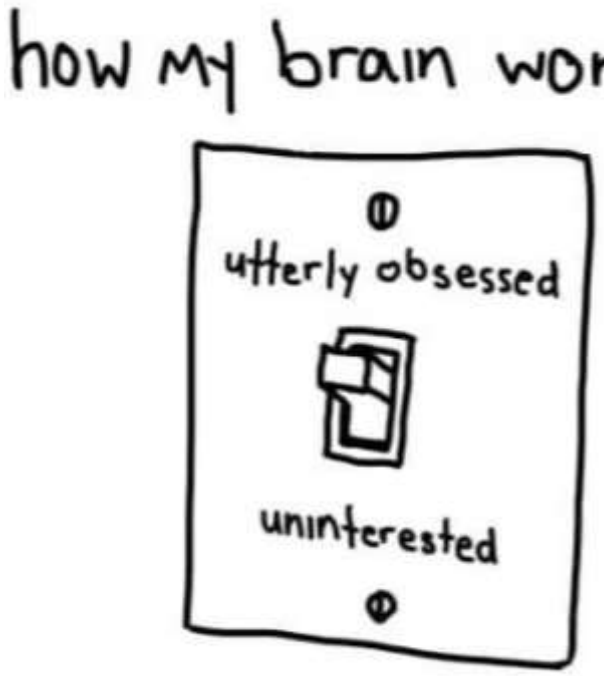
ADHD is also a neurodivergence. Some people are Autistic and ADHD, and some are just ADHD or just Autistic. Autism and ADHD are not the same, but there are overlaps. Autism by itself has a strong sensory processing layer. ADHD by itself has a strong impulsivity, with an often minimal sense of danger. Someone who is Autistic and ADHD often has fixated interests, but can switch fast to other interests (lack of object permanence), can be much more strongly opinionated and passionate, but also highly affected by rejection.



Some key characteristics of ADHD are:

- Bored easy.
- Need lots of things to do which burn energy.
- Easy to become explosive, not easy to calm down.
- Unlikely to want to focus on hard work, prefer easy reward.
- Need shorter tasks which are enjoyable.
- Focus on fun things, minimise any focus on work.
- The 'hard yards' are not appreciated by an ADHD brain mostly; they are avoided and dreaded.
- Very hedonistic in nature.
- Calms down only via distraction – never through conversation or attempts to 'diffuse'.


ADHD
IMPULSIVITY.
SHORT ATTENTION SPAN.
POOR WORKING MEMORY.
POOR PLANNING SKILLS.
TIME BLINDNESS.
DEPRESSION WHEN UNDERSTIMULATED.
LITTLE SENSE OF DANGER.
MAKING CARELESS MISTAKES.
NO MOTIVATION FOR TASKS YOU ARE NOT INTERESTED IN.
SENSORY ISSUES.
HYPERFIXATIONS.
STIMMING.
AUDITORY PROCESSING DISORDER.
TALKING A LOT.
FINDING IT HARD TO MAKE FRIENDS.
EMOTIONAL DYSREGULATION.
INTERRUPTING CONVERSATIONS.
REJECTION SENSITIVE.
LACK OF OBJECT PERMANENCE.
EXECUTIVE DYSFUNCTION.
SLEEP PROBLEMS.
AUTISM
TAKING THINGS VERY LITERALLY.
HAVING THE SAME ROUTINE AND GETTING ANXIOUS IF IT CHANGES.
BEING UNCOMFORTABLE MAKING EYE CONTACT WITH OTHERS.
LIKING TO CAREFULLY PLAN THINGS BEFORE THEY HAPPEN.
NOT UNDERSTANDING SOCIAL "RULES".
NOTICING SMALL DETAILS THAT OTHERS DO NOT.
GETTING UPSET WHEN SOMEONE TOUCHES YOU.
GETTING VERY ANXIOUS ABOUT SOCIAL SITUATIONS.
@tfw-adhd


how my brain works.
utterly obsessed
uninterested

Benefits of ADHD

Any neurotype has its considerable benefits and perks. The ADHD brain can be quite brilliant and lead to wonderful success, a heightened ability to remain calm in difficult situations and amazing creativity.

Have a read through some of the perks/benefits of the ADHD brain on the following page.

1. Calm during a crisis

When others are in a crisis, we can be cool, calm and under control. People with ADHD often pursue and excel at careers like ER doctor, nurse, police officer, journalist, athlete, or entertainer. In contrast, we may struggle to pay attention in calm situations; we need tips and tricks to help us stay on task.

2. Creative

One study showed that people with ADHD tend to be more creative than people without ADHD. For this reason, people with ADHD can also excel in creative careers. Just don't forget that structure and organisation is important when following through on those creative ideas in order to see them to completion.

3. Intuitive

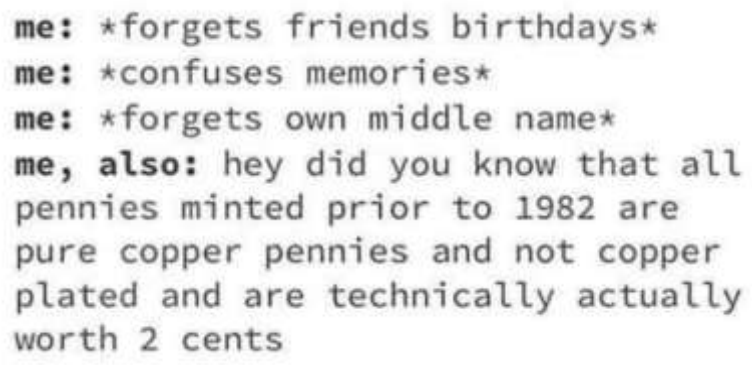
ADHD brains often take longer to process sensory information (sights, sounds, etc.) than typical brains. While this may seem like a downside, it can actually mean we notice things that others don't. In other words, we can think outside the box.

4. Spontaneous

People with ADHD are often quick starters that tend to jump right into a new project or idea. Instead of getting stuck following the status quo, we are often motivated to try new things. Planning is often a good thing, but too much planning can also mean you might miss out on a time-sensitive opportunity or that you don't get anything done.

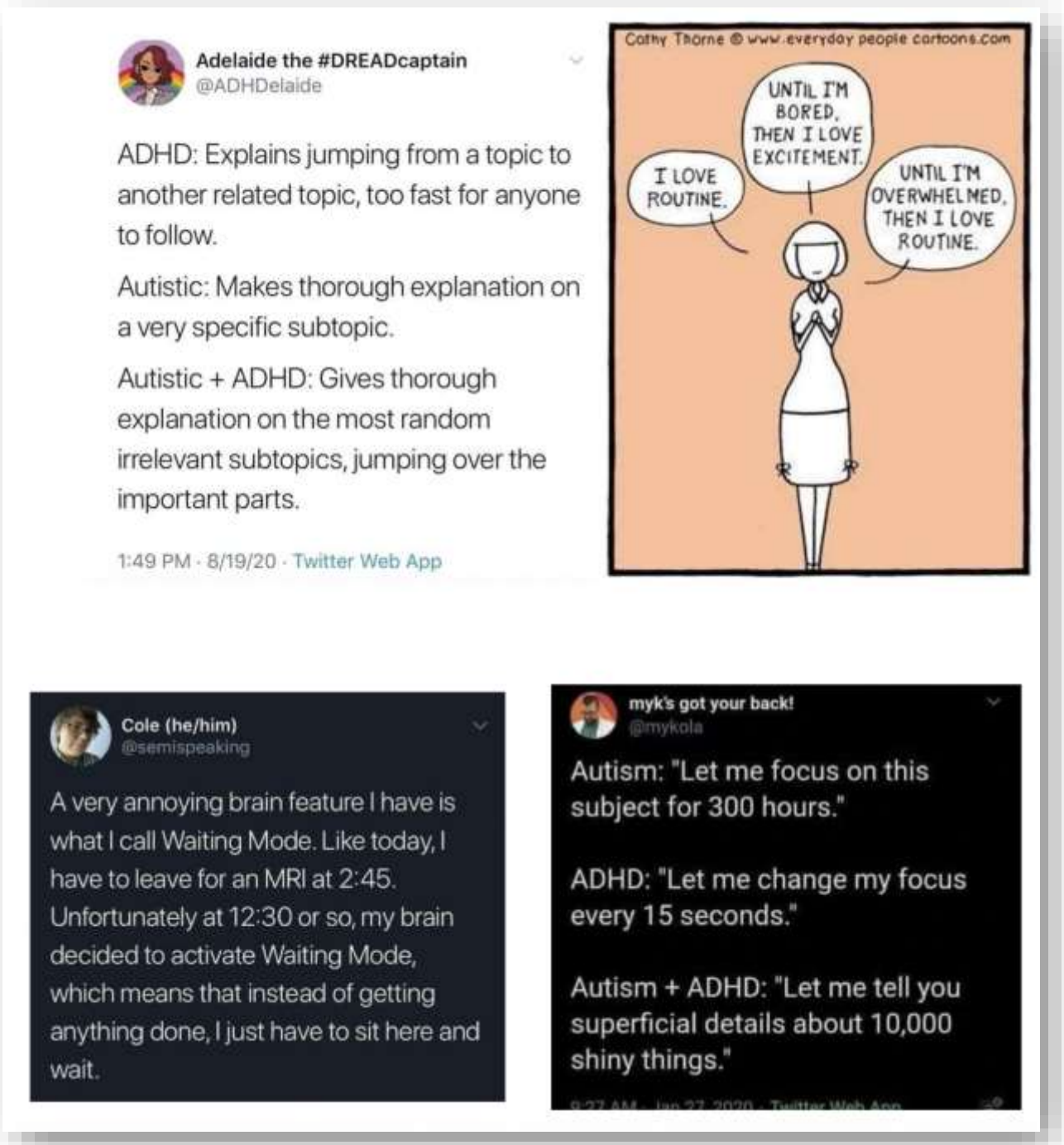
5. Curious and driven

People with ADHD tend to focus really intensely for long periods of time on subjects they're interested in; this is called hyperfocusing. This is great for working on our hobbies or studying a subject we enjoy. And if we happen to hyperfocus on one thing when we should be doing something else, we usually have people around us to give us a reminder.




ADHD &
hurtful assumptions
Answering "I don't know" means I'm lying.
I genuinely don't know or my mind goes blank.
When I say "I don't know" it's not an excuse. It's hard to identify the reason when I've been told so often there is no reason I couldn't have done it.
Without learning how ADHD affects my daily life, I won't have the words to describe what I struggle with.
Try asking more precise questions! Instead of "Why didn't you clean up?" Ask: "At what step did you get stuck?"
I want to make everything about myself.
I have a different way of communicating.
I like sharing similar experiences and stories to what you tell me. To me that means: "I think I understand! I hope my story resonates and helps you."
I don't do this with the intention to switch to talking about me.
I'm not answering your messages because I'm ignoring you.
I got distracted or thought I had already answered.
There are many reasons why I don't answer messages. Sometimes, my social batteries are just drained. Other times, I have trouble setting boundaries because I'm afraid of rejection.
The longer and more often I don't answer, the harder it gets to apologize and write at all.
"You're just trying to get out of doing chores."
I have trouble with multi-step tasks and verbal instructions.
ADHD affects my ability to put tasks into chronological order and organize them by importance. That means I will often end up being stuck before I even start - especially if the instructions don't specify an order in which to do things or leave questions open.
"You are so random!"
You can't catch up to the speed of my thoughts.
My brain is incredibly fast and good at making connections and associations. I'll already have carefully considered 20 options before someone finishes talking.
I often only share the end-result of my thoughts, but that doesn't mean they came out of nowhere.
"Well then you should have studied more!"
ADHD makes it hard for my brain to access information.
When I can't repeat what was taught in class or answer simple questions, it's assumed I didn't study enough, that I'm stupid or refuse to cooperate.
But sometimes, my brain just can't access information. Even things like names of vegetables or my own birth date.
ADHD Alien
Resources explaining ADHD and Executive Dysfunction more indepth:
"Taking Charge of Adult ADHD" by Russell A. Barkley, phD
"Delivered from Distraction" by Edward M. Hallowell, MD and John J. Ratey, MD
"Executive Functions" by Russell A. Barkley, phD

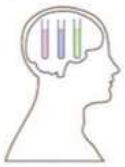
Some popular views of ADHD and Autism / ADHD from the Autistic/ADHD community are provided below for thought and consideration.



ADHD

A PHYSICAL BRAIN DEFICIENCY IN PRODUCING SUFFICIENT LEVELS OF BRAIN CHEMICALS (NEUROTRANSMITTERS)

NO ADHD

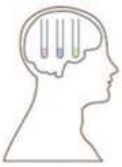


DOPAMINE = MOTIVATION & MEMORY

SEROTONIN = MOOD, SLEEP, APPETITE & MEMORY REGULATION

NORADRENALINE = FIGHT, FLIGHT OR FREEZE

ADHD



A PHYSICAL DEFICIENCY <u>NOT A CHOICE</u>

NOT CONTROLLABLE BY WILLPOWER

NOT CONTROLLABLE BY DISCIPLINE

ADHD & EXECUTIVE FUNCTIONING

Executive function is a set of mental skills in the frontal lobe of the brain that we use every day to learn, work, and manage daily life. ADHDers can be an average of 30% delayed in the maturity of their executive functioning. The brain reaches maturity in the early 30's. Deficiency in certain brain chemicals and, or, challenges with the part of the brain where executive function is located can affect and make it difficult to do the following:-

Working memory	Internal voice
Initiation of tasks	Foresight & hindsight
Adaptability	Self-awareness
Prioritisation	Self-regulation
Organisation	Filtering
Flexible thought	Re-focussing
Planning	Emotional regulation
Time management	Ability to shift task
Internal regulation	Multi step complex thought
Decision making	Sustaining task

Biological Age	Possible Delayed Executive Age	Biological Age	Possible Delayed Executive Age
3	2	17	11.3
4	2.6	18	12
5	3.3	19	12.6
6	4	20	13.3
7	4.6	21	14
8	5.3	22	14.6
9	6	23	15.3
10	6.6	24	16
11	7.3	25	16.6
12	8	26	17.3
13	8.6	27	18
14	9.3	28	18.6
15	10	29	19.3
16	10.6	30	20

ADHD & RSD
REJECTION SENSITIVE DYSPHORIA

"RSD is extreme emotional sensitivity and pain triggered by the perception – *not necessarily the reality* – that a person with ADHD has been rejected or criticised by people in their life". - Dr William Dodson MD

These extreme, intense, instant, reactions can be internalised or externalised and can be seen as –

Defensiveness	1000% effort & nothing good enough
Defeatist	Impressive instant rage
Fear of failure	Unreasonable attacking
Oversensitivity to criticism	Suicide ideation
Blame of others	Blind unfiltered temper
Apathy / uncaring	Dismissive of others
Major depression	Minimisation of others
People pleasing	Justification of action

50% of people assigned court-mandated anger-management treatment have previously unrecognised ADHD. – Dr William Dodson MD.

Therapy alone may not help due to the instant ***'red mist'*** intense reaction. There are certain medications that can help with this issue. Alpha agonists such as Guanfacine (Intuniv) and Clonidine are known to help and also MAOI's (Monoamine Oxidase Inhibitors) which are prescribed off-label.

Remember it is the perception of the person with RSD, ***not necessarily the reality of the situation,*** they are responding to.

ANXIETY

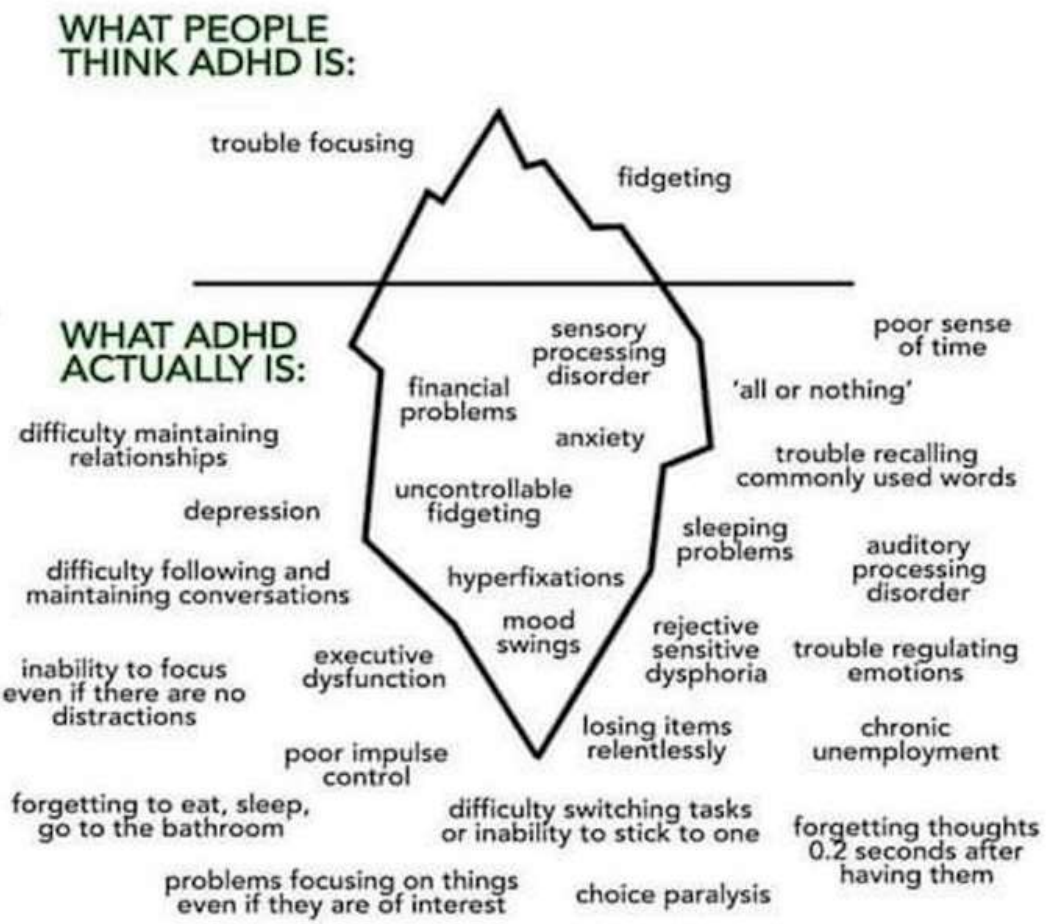
HOT FLUSH FEAR HEART PALPITATIONS SECOND GUESSING
SHORTNESS OF BREATH FATIGUE OVER-PLANNING NAUSEA
FOCUS ON NEGATIVE UNMOTIVATED WHAT IF? INDECISION
DISCOUNT POSITIVE OVEREMOTIONAL TIGHT CHEST ANGER
LOSS OF APPETITE CATASTROPHISING MUSCLE TENSION
HEADACHE SWEATING DESIRE TO CONTROL EVERYTHING
UNCONTROLLABLE WORRY DEFIANCE IRRITABILITY TENSE
FRUSTRATION AVOIDANCE EXCESSIVE WORRY INTOLERANCE
OVERTHINKING WORRY ABOUT FUTURE PANIC ATTACKS
NUMB TO FEELINGS TREMBLING SCARED STOMACH CRAMPS
RESTLESSNESS INCREASED HEART RATE AGITATION
NERVOUSNESS UNREASONABLE OUTBURSTS UNCERTAINTY
HYPERVENTILATING DISTURBED SLEEP EXTRA SENSITIVE
MINDREADING WORRY OF PAST EVENTS EXTRA EXPECTATION
DEPERSONALISATION FEEL DISCONNECTED EXTRA PRESSURE
NEED REASSURANCE STRUGGLE PAY ATTENTION OR FOCUS
ALL OR NOTHING ATTITUDE WOUND UP EDGY OBSESSIVE

LACK OF SEROTONIN

(vitamin D + omega 3)

THE ADHD ICEBERG

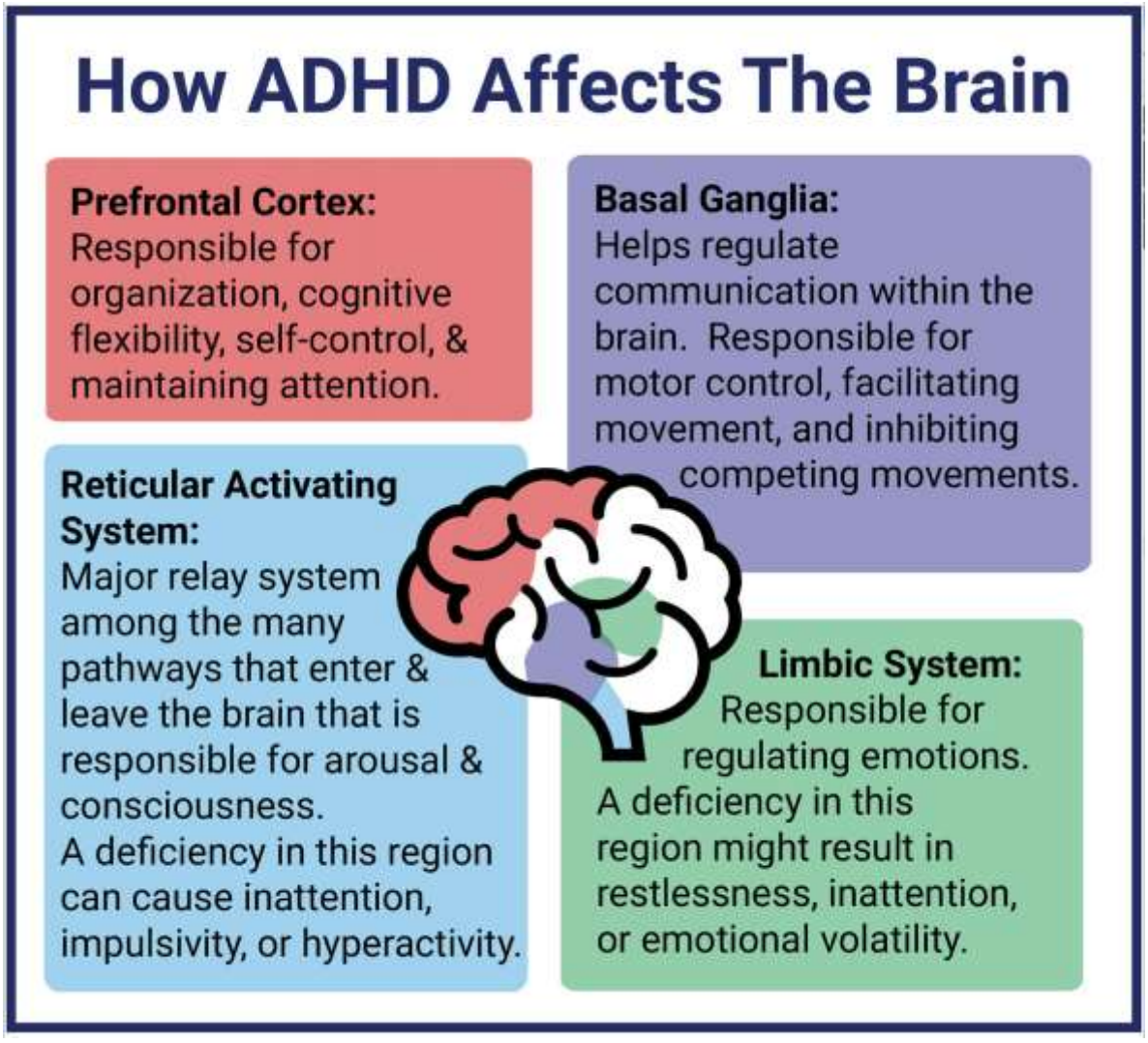
@FINUCCINIALFREDO



ADHD Summary Comments

The best way to work with people who have ADHD is that they are seekers of enjoyable experiences and find quiet, still spaces, with expectations of socially regulated conduct to be terrifying. They often love rules that they can follow and can be staunch advocates for rules once they know they exist and know they can follow them. There is often boundless energy that exists with those who are ADHD, but this can be coupled with total exhaustion if they don't acquire the sensory input they need, with the balance they require. The best way to move forward and work with someone who is ADHD is to:

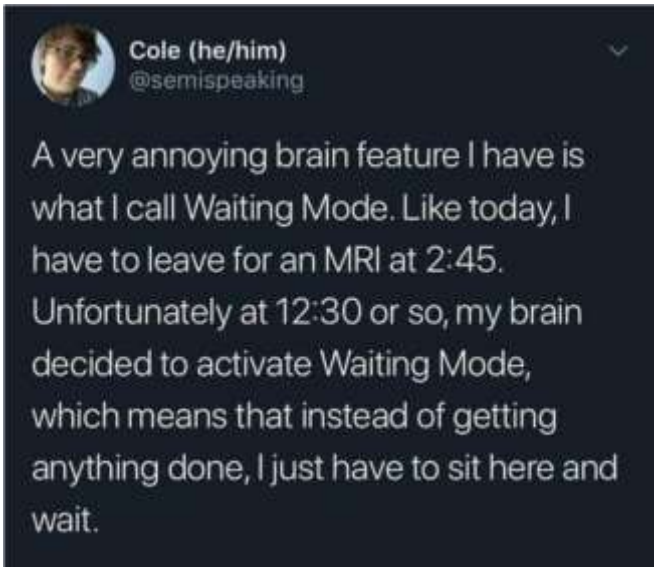
- Use distraction as the primary response to difficult situations.
- Space and break up boring or monotonous tasks with fun, short tasks to make it easier to get through.
- Use consistency in expectations to help manage executive functioning complexities.
- Use reminders and prompts to help the person remember what they are up to.
- Enable the person to have control over their life and wellbeing.



Getting Stuck, Perseveration & Hyperfocus

Getting stuck and perseveration

This is when a person cannot move forward, past something. Often 'feelings' of good, sad, happy, excited, anything, can be overwhelming to an autistic person and can keep them 'stuck' in these feelings for quite a long time. Getting stuck can happen for a number of reasons. This can be due to Autistic perseveration, such as when someone feels guilty or pressured about a social expectation they cannot meet and cannot find a way to resolve, and it can also be due to the Attention Deficit Hyperactivity Disorder (ADHD) hyperfocus. When an ADHD person hyperfocuses, their entire brain becomes infatuated with something, and it just plays in a loop in their mind. Thinking about this thing at this time is nurturing and feels good and doing/saying/thinking about the hyperfocus becomes a stim (self-stimulatory behaviour) while they are in the loop and stuck in the hyperfocus.



'Perseveration' has been defined as:

> *"The continuation or recurrence of an experience or activity without the appropriate stimulus (MacNalty, 1961; Dorland, 1965). The term perseveration was first coined by Neisser in 1895. Goldestein (1948) described perseveration as an inability to inhibit a previous thought."*[8]

Perseveration and/or getting stuck can present in a few different ways. Getting stuck happens mostly with people who are both Autistic and ADHD and can be due to overwhelming amount of thoughts which either:

[8] Gillan and Brockman Rubio https://www.sciencedirect.com/topics/medicine-and-dentistry/perseveration

a) Make the person unable to do anything else because they feel overwhelmed by the high degree of thoughts pumping through their head and feel unable to do anything because they cannot stop thinking about a particular thing, or everything, OR
b) Make the person hyperfocus on one particular thing/script/idea/person/situation and just keep repeating it or doing it in a loop. It's very common with those who are ADHD that things stuck in a loop can be controversial, scandalous, inappropriate, or rude. This is because there is so much energy in 'devious' and 'mischievous' and it gives extra dumps of dopamine in the brain when the subsequent excitement happens as a result of this behaviour. This only pushes the loop to last longer.

Perseveration means that the person is struggling to do something because they cannot shift their hyperfocus from something else.

Sometimes it regards an exciting thing about to happen and sometimes it's based on fear of something, or pressure or anxiety regarding an interaction. Very commonly, transitions will lead people to get stuck. They aren't ready to stop doing one thing and do something different and the feelings associated with change become overwhelming.

The reason for getting stuck can be different for each person. More often than not, it's due to a sensory related matter, such as the person struggling with interoceptive input (thoughts and feelings about something) and not knowing how to cope with it

Some of the reasons for getting stuck could include these listed on the following pages.

Sensory Reasons

There is one sensory modality which is often forgotten by people. This is **interoception.** Interoception relates to our internal body sensations, including our bodily functions and processes, registration (or lack of registration) of our feelings of being happy, sad, angry, guilty, nervous etc. It is not uncommon that a lack of interoception registration (e.g., People who don't feel or understand their own interoceptive input) become stuck due to social expectations and norms as they don't feel confident navigating them and know that no response is sometimes just as socially repulsive as the wrong response. This double-edged sword can leave some people unable to do anything regarding a social expectation as they cannot manage doing nothing and don't know how to respond to resolve the matter.

This often is seen as 'inattentive ADHD' which is described further below. Often the person becomes overwhelmed by the interoceptive sensory input which tells them there is a social expectation that they need to meet. Yet, they feel overwhelmed with the pressure of any possible response they can think of. As a result of this, they often choose to do nothing at all and refuse to engage respond or reply to the social demand.

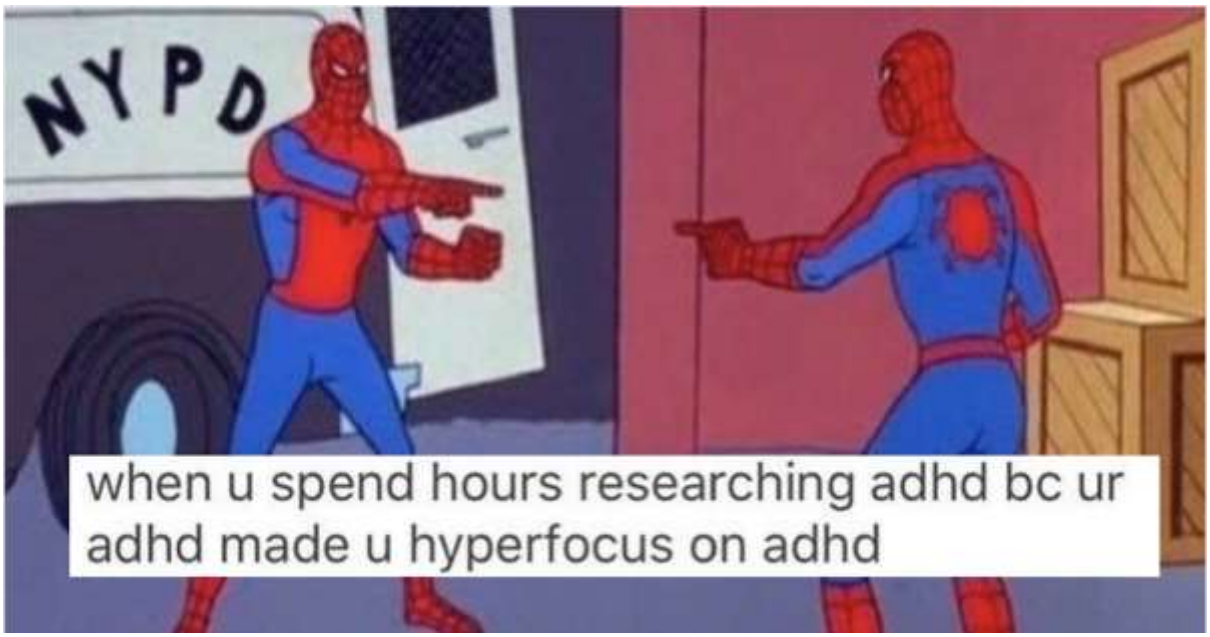
ADHD - Inattentive hyperfocus

This is when a person with ADHD is overwhelmed by everything they have to do, that they can do nothing. It's common for people with afternoon appointments that they will spend their day doing nothing as they cannot manage other tasks until the afternoon appointment is done. Some call this 'waiting mode'. For children, this can look like they are being vague and unresponsive, but they are sometimes just totally overwhelmed and hyperfocusing on how overwhelmed they are that they are unable to do anything until they can break things down and unpack the issues leading to this experience.

ADHD – Overactive brain

The overactive brain exists with some people with ADHD who cannot stop thinking and have a hyperactive brain. This is sometimes in conjunction with a hyperactive body (e.g., A body which craves and needs excessive vestibular sensory input) and sometimes the person doesn't have a hyperactive body, but still has a hyperactive brain. People like this have brains that act as magnets to the most interesting stimulus at any one time and can bounce from topic to topic with intense speed. Essentially the brain is seeking continual dopamine hits, which it gets from what it perceives to be 'interesting stimulus', but this can be found in 25 different things per minute if sufficient stimulus exists. An overactive brain can also hyperfocus all components on just one thing and have such intense fixation on it that the brain cannot think about anything else and be stuck in a perseverative loop regarding this

topic. If the topic is controversial then it's even easier to get in this loop as the attention and focus the person gets from first mentioning or doing this is a dopamine hit itself.



Exploring the Hyperfocus

People with ADHD often have issues with their hyperfocus. The hyperfocus means that their brain becomes quite consumed with things and when they focus on something, they can focus with such intensity that many other things are totally disregarded as a result. The hyperfocus can be very consuming and when the person is hyperfocusing their topic of interest becomes a self-stimulating thing and it's nurturing and feels good to keep thinking about it. Hyperfocusing on

something sometimes provides a dumping of dopamine which makes the person feel good, so it's literally addictive when the person is in the mode. When someone is hyperfocusing, the only way to help them to shift their focus is to provide them something alluring for their brain to help share the focus. This helps them get unstuck from a hyperfocus, but often takes a lot of energy.

People who are Autistic and with ADHD hyperfocus on issues with such intensity that they literally are unable to move past them until the perseverative loop is over, without significant distraction. Focusing or discussing these issues more makes things worse and can lead to amplified behaviour of obsession. Issues with perseveration (e.g., Intense focus on something) are best managed by:

- Increasing other preferred input, such as vestibular movement from the person.
- If possible, find a way to give them an opportunity to access movement and sensory input without the person / thing which they are obsessing about close to them. This enables them to force themselves to switch their focus onto other things.
- Don't give energy to the obsession. E.g., A child saying rude words or saying something offensive which has become obsessional due to how controversial it is (and how much it breaks the rules) can become so excited by this that they get themselves in a perseverative loop easily. The best response is to appear disinterested in what they said, provide minimal response and focus on something different.
- A hyperfocus (from ADHD) is very hard to get out of. All the person's brain is fixated on this thing/situation/person at this time, and it just loudly keeps playing on repeat and thinking about feel comfy and right. When someone has a hyperfocus, doing the thing they are focused on is like a stim (self-stimulatory behaviour) as it feels good and nurturing, regardless of how much trouble they are getting in.

Example Situation: Bob only 7 years old and Autistic / ADHD and has become a bit obsessed with saying *"girls have boobies, girls have vaginas, I'm going to see them".* He originally got this off a you tube clip he watched apparently, but he's stuck in a bit of a loop saying it and has gotten in lots of trouble and his parents are quite embarrassed. The teachers have given him time outs and stern warnings about saying this, but it's only made it worse and now Bob

is saying it quite a lot and everywhere. Bob also loves building things, such as towers and buildings, but this interest has taken a back seat right now due to this hyperfocus.

Bob: "*Girls have boobies, girls have vaginas, I'm going to see them".*

Me: <ignores this, pays no attention, doesn't respond, or show in my facial expression that I even heard it>

Bob: "*Tara, did you hear me? Girls have boobies, girls have vaginas, I'm going to see them".*

Me: "Nah, that's not funny, I don't care. Hey <increased enthusiasm in my tone now> I just saw how Graeme built that amazing tower over there, Graeme is so clever. I wonder if you'll be able to build a tower like that. You used to be the best at towers, I think Graeme is beating you now."

Bob: "Yeah, but Tara <giggles> *girls have boobies, girls have vaginas, I'm going to see them".*

Me: "I'll be back in a minute, I want to ask Graeme to show me how to build that. Oh goodness, look at how tall it stands, holy dooley, I don't know how he's done that, it could collapse any second and then – oh my gosh – it could knock Julie's whole creation over. Oh no, Julie isn't going to be happy if Graeme knocks all her hard work over".

Bob: <will appear a little frustrated that he's not getting the feedback he's wanting, but will be starting to get interested in this tower now>

This energy needs to be maintained in order to help Bob shift his hyperfocus away from his script he's saying and onto something different. The key steps are:

1. Disregard the scandalous hyperfocus. Don't play into it, punish it or highlight it. The person cannot stop it right now and are stuck in this loop. Providing any more energy to it will make it worse until the only way to stop it will be forced masking from fear-based punishments. These will always result in explosive meltdown behaviour.
2. Provide a new distraction that the person would have previously enjoyed and loved. This needs energy and repetition to make it work. It's not easy to have this level of energy, but without it, the person won't shift their hyperfocus.
3. Give excessive movement breaks where possible. Helping the person move their body in a whole different way will help them to get unstuck and shift their focus to something else.

4. If the focus is based on a person, try to give them an opportunity to gain sensory input without being in that person's space. Give them a chance to breathe without the obsession right there.

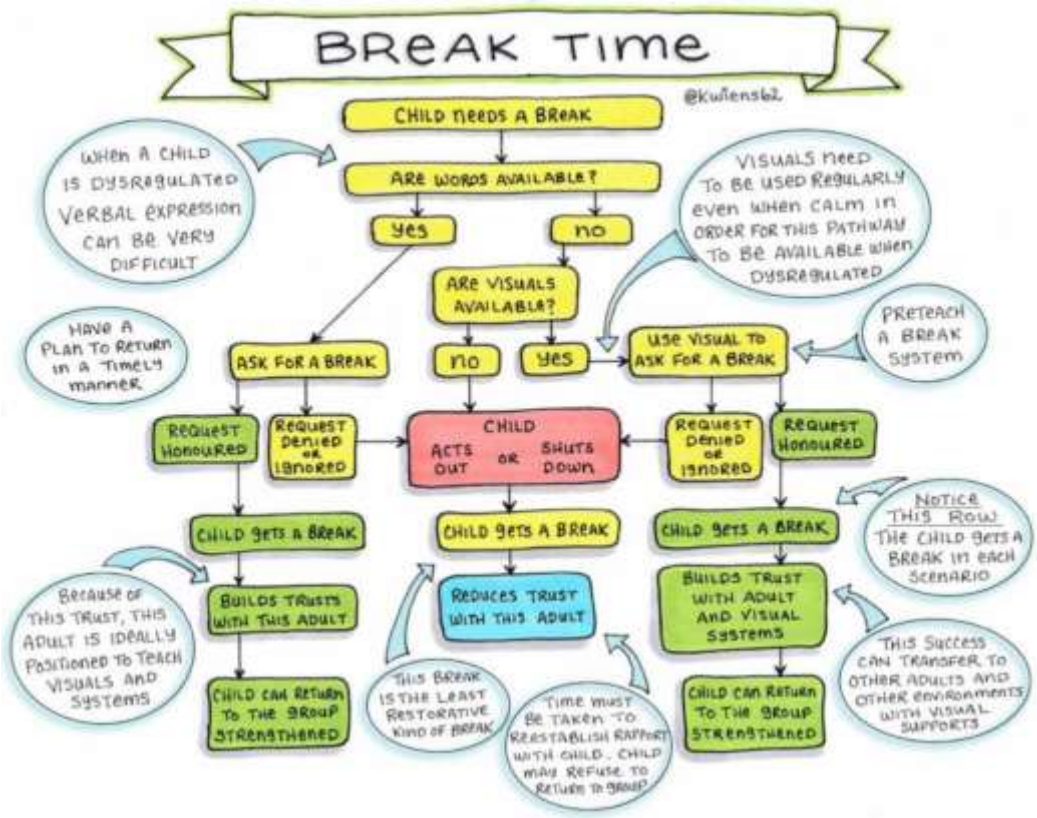
NOTE: It's acknowledged that for many, it's hard not to punish a child who is swearing or saying rude and inappropriate things. But there is no behaviour change in punishment, only trauma and forced masking from fear of loss and restriction. Children want to be good; they want to be liked and they want to feel valued. Behaviour such as controversial hyperfocusing and getting stuck is happening because they lack the skills to not do this, and they are in distress and struggling. No child does this for fun. It's not fun to be in distress and to be constantly getting in trouble.

Change the stimulus – provide an opportunity for a new focus

To help someone re-align or shift their hyperfocus, it's helpful to provide them something different to think about. Adding opportunities to gain sensory input can be a great way for some, as some children are nurtured through meeting sensory needs such as gaining vestibular input.

Never take away opportunities for movement in response to complex behaviour as this will inevitably lead to increases of this behaviour, even if there is short-term relief.

Fear-based punishments such as suspensions and not being allowed their break time will sometimes work to stop unwanted classroom behaviour but using methods like this traumatises an Autistic / ADHD child as you're literally removing the thing they need, not teaching any lessons. Most commonly the reason an Autistic or ADHD child is in an unhelpful perseverative loop is they are either hyperfocused on something they cannot control and/or they are feeling deprived of sensory input they desperately need to remain regulated. Both of these situations or possibilities are helped by increasing opportunities to gain sensory regulation from increasing the opportunity to access other sources of input.



Never use reward charts / star charts in classrooms with children who are ADHD – This is BEYOND DANGEROUS.

Star charts and reward systems are toxic. Many theorists now have come out with evidence-based research which shows the danger in using manipulative systems like star charts and behaviour charts in classrooms.

You might remember this episode (pictured) of SpongeBob SquarePants where he had one of his stars removed from his star chart for his behaviour. SpongeBob burst into tears and slithered down in his chair, despondent and devastated.

Star charts and reward systems are toxic. They make children suppress their needs to gain public validation that they are behaving the way that the authority figure deems to be 'good'.

Star/reward charts force masking (e.g., Make the child suppress their own needs) and star/reward charts result in public humiliation when a child isn't successful.

Let's look at this example. This is a *note from the Author:*

I am not good at maths, definitely never understood calculus. It wouldn't matter what reward existed, I couldn't just suddenly understand calculus without a lot of patient training and education. If I was in a position where suddenly the only way to be considered successful and to gain a reward was to demonstrate I knew calculus, I would fail. It doesn't matter if I really want the reward and if I am ashamed of the public humiliation I would endure when I don't get the reward, all these motivations still don't make me magically understand calculus. Calculus is particularly hard for me and I can't just learn it quickly, especially now that I feel pressured due to these possible rewards.

I am ADHD myself. I have pride in what I can do and I like to be correct and I like to win. I also love to make an impact and love to shock people. Due to all these reasons, I would be likely to go overboard in response to this 'reward for calculus' that I will never get. I would mock it; I would make my impending failure totally epic!! This is because my brain is ADHD and I don't do anything in a small way or by halves. I am extreme a lot of the time and I love to make a dent. For me, if I was in a classroom with a reward system like this and I had to demonstrate behaviour that I knew I would not be able to demonstrate, then I would just make a mockery of the whole thing. I would do this as it's the only way I know I can have fun and I would do it because it's unfair that I can't get the reward for reasons that aren't in my control. It's not my fault that I don't have these skills. It's not my fault that my brain doesn't understand maths.

Reward charts for the ADHD brain are either an intoxicating driver of behaviour which makes us suppress all our actual needs, mask heavily while in the reward zone and hyperfocus only on the behaviour needed to gain the reward, OR they are the subject of hopelessness, public humiliation and feeling helpless and useless and thus often the instigator and motivator of other behaviour.

There are many resources about the damaging effects of star charts, reward systems and classroom behaviour medication tools.

The link below has plenty (50+) of these articles and resources for further information. There are also great international professionals with evidence-based, published work on the harm they do, including Greg Santucci, Mona Delahooke PhD, Dr Ross Greene and others.

https://docs.google.com/document/d/1JiBpVxSY0hha6BaUGRM6iRbO2lgU2LI3fmNARyNy8h4/edit?fbclid=IwAR0ioTvfXtZJCCaaX6adkoJ_ykxTyL5tP9tq8KUJnuXnQyMaITnr-7BThDA

Rejection Sensitive Dysphoria (RSD)

"It hurts a lot more when I don't feel wanted and liked"

RSD is part of having ADHD, just like most other things, us ADHD'ers also hyperfocus on rejection and feelings. RSD presents differently in everyone. I've heard some ADHD'ers say they don't live with it, but research indicates it's a part of ADHD in all people, but it presents very differently in each person and the individual's coping mechanism can cover the signs of it. In a nutshell, RSD is a heightened hypersensitivity to what people think of you.

As simple as that sounds, it rarely looks like weakness. RSD can look like:

- Someone who acts extremely tough and manipulative and targets and actively attacks people who he thinks don't like him. Often perceived as a bully, this child/adult is actually secretly and fundamentally scared of not being liked and has created some strong walls and self-protection strategies.
- That little twice exceptional person who wants to desperately 'get it right' and have the teacher happy with him, that he focuses so much on his work and has extreme levels of anxiety about getting things right. Even constructive feedback feels like a brutal kick in the guts to this person and he/she experiences excessive depression following feedback which is not glowing.
- That child who only perceives "love" from those people whose love language is words and affectionate touch and who feels detached and separate from anyone who doesn't go over the top in providing them positive emotional validation in an extremely heightened way.
- That child who loves playing with other kids, but as soon as one of the children exclude him/her or say something to make the child feel like they aren't wanted/part of the group, the child has a raging meltdown or total emotional breakdown, or some type of overly dramatic reaction.
- That person who makes strong connections (friends / partners) super-fast and is really close to people very quickly. This same person will feel extremely gutted, sometimes suicidal when there is a fight of any kind as they feel this connection is lost due to the slightest sign of unrest or disappointment.

- That child always needing to be told they are loved, and their mother isn't mad at them. Times when the child is corrected *"Jenny, please don't spill the milk like that"* results in a massive meltdown as this form of correction is over felt (high registration) and therefore they feel this correction as a brutal criticism and a sign they aren't liked.
- That teenager who pushes people away, has excessive anxiety regarding new people and/or emotional connections of any kind and displays lots of self-loathing behaviour, negative self-talk, possible self-harm, makes comments that people don't like them anyway, lives with ongoing depression and signs of feeling rejected.
- That person in a relationship who has a total meltdown at any fight with their partner and ends up in tears for hours until the partner assures them that they are ok. They are known for catastrophising and thinking their relationship is over due to minor fights.

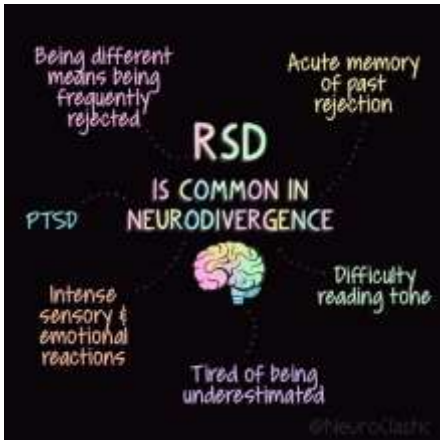
Or, with regard to relationships, it can even look like:

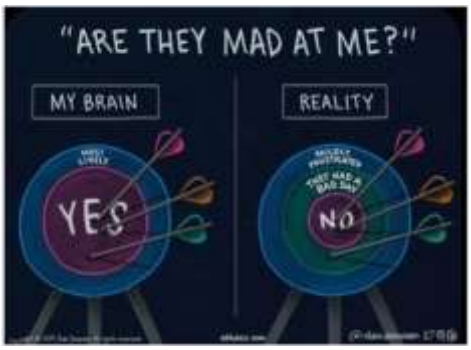
- That person who appears cold and detached at fights and refuses to show their emotions at all, becoming extremely distant and removed at any sign of an emotional exchange. This is often those who are aware of their profile and have trained themselves as they are aware of how painful letting themselves feel anything really is.
- That person who needs a lot more validation a lot more than their peers and constantly has negative self-talk, telling themselves they are crap and they can't do stuff and people don't like them. They are always worried they won't fit and are well known to mask around people.
- That person who is overly emotional and has ups and downs with their moods frequently. This person can be the one who hears from one person "*gee, you post a lot of pictures of your dog on Facebook"* and the next minute, they decide to take a break from Facebook all together, or make a dramatic post saying something like "*it seems everyone is sick of posts about my dog"* or "*If you are all sick of seeing my posts about my dog, just unfriend me".* This person is likely to become extremely emotional regarding any fights with friends and catastrophise frequently.
- that person who becomes 'naughty' every time their mother plays with their sibling or spends time with her husband. Often children with RSD struggle the most with their

parents as this is the basis and foundation of their emotional bond. Parents of children with RSD are likely to be loaded with guilt as they are always made to feel that they are never enough for their child.

Warning - don't be deceived about RSD, it is essentially (in essence) a heightened registration of interpretive sensory input (feeling internal feelings to a much greater extent). Those with RSD feel a lot more than others, so their experience is heightened - as is the case with any sensory processing profile. Many people with RSD will present as overly emotional **and conversely** many people with RSD will appear cold, detached and very unemotional. This is the nature of the complexity of managing big emotions and the diversity in how we each choose to do this.

(Pics below by Neuroclastic, ADHDD.COM and Spaghetti Brained ADHD)





RSD is a component of ADHD and presents incredibly differently in people. In some, it may look like an overwhelming need for attention, a hypersensitivity to criticism, or even complete withdrawal from social interaction.

"Rejection sensitive dysphoria (RSD) is an intense emotional response caused by the perception that you have disappointed others in your life and that, because of that disappointment, they have withdrawn their love, approval, or respect. The same painful reaction can occur when you fail or fall short of your rather high goals and expectations. RSD commonly occurs with ADHD and causes extreme emotional pain that plagues both children and adults — even when no actual rejection has taken place.

Rejection sensitive dysphoria is difficult for people with ADHD to describe, but all who have it agree that it feels awful. Indeed, the term dysphoria is literally Greek for "unbearable." Often those with RSD hide these intense emotional reactions from other people and feel ashamed of their vulnerability. The condition often triggers a profound and wide-reaching sense of failure, as though the person with RSD hasn't measured up to personal or external expectations.[9]"

People with RSD have the most difficulty with people they have strong connections to. The stronger the connection with a person, the more heavily impacted they are by any perceived

[9] https://www.additudemag.com/rejection-sensitive.../amp/

rejection. In some, this can result in meltdowns, aggression or self-harmful behaviour when they feel rejected by those close to them.

Feeling rejection as a person with RSD can completely overwhelm their entire body. When they experience this overwhelming amount of emotion (sometimes referred to as an RSD meltdown), they have little to no control over their actions. This could present as significant emotion, self-harm, or wild raging aggression. All they will be able to focus on is the severe hurt they feel. In the aftermath of an RSD meltdown, the person may not understand why they lost control, and feel that those around them are disappointed in them for doing so and having the meltdown. This is the cycle of RSD.

Common Aspects/Presentations of RSD

There are many different presentations of RSD, as the extreme sensitivity affects people so differently. Below are some of the more common aspects and ways it can present.

Attention & validation seeking – A person with RSD has an overwhelming need to seek validation and attention from others and will often feel little self-worth without it. In some this looks like looking for an excuse to continue a conversation (e.g., asking for help with things they know how to do).

Hypersensitivity to criticism – Someone with RSD will feel extreme anguish when they feel they are being criticised or have done something wrong. They will often be hyperaware of the behaviour of those close to them in any way they can (e.g., body

language, tone of voice, facial expression) to look for signs of the person being upset with them, which is what can lead to them perceiving rejection when there isn't any.

Many people with RSD will also get distressed at the possibility of others being informed of things they have perceived to have done wrong.

Seeking many 'acquaintance level' relationships, but little to no deeper relationships – The deeper the relationship with a person, the more hurt the person with RSD is by any perceived rejection from the person. This can then lead to a person experiencing severe trauma in meaningful relationships, which can cause these people to try to meet their need for social interaction by having a large number of shallow friendships in order to protect themself from the pain they associate with meaningful relationships.

Withdrawal from socialisation – As mentioned above, some people with RSD experience severe trauma from the pain they have experienced in previous relationships. This can cause a person to completely withdraw from socialisation as an act of self-preservation. However, it's important to note that if a person with RSD isn't getting their need for validation and acceptance met, this can lead to meltdowns, aggression and/or severe depression.

Hesitance to meet new people – Meeting a new person can be terrifying for someone with RSD. When someone with RSD knows a person, they know how much validation to expect, and generally where they stand with the person. None of that knowledge exists when meeting someone new, nor does knowing how to act in order to be liked. They feel they are opening themselves up to rejection.

Fixations on certain people – Someone with RSD will commonly fixate on a person that inconsistently provides them with validation. If a person were to offer a lot of warmth and validation one day and the following day seem preoccupied or distant, the person with RSD may obsess over seeking out the amount of warmth and validation they were receiving the day prior.

Avoidance of activities – Some people with RSD will avoid some, or even all, activities due to a debilitating fear they may fail.

Rude or abrasive towards people – This is generally a defence someone with RSD will have in response to their need to be liked and accepted. A person with RSD is so affected by this overwhelming and uncontrollable need that some try to assert control by acting as though they don't care or even going to the extent of trying to ensure a person won't like them.

People pleasing – A person with RSD may work so tirelessly to please those around them that put their own goals/needs/wants aside, to please others. Some will even act like someone they aren't because that's what they feel will make them feel accepted by the people around them.

Ways to Manage RSD

Managing RSD is extremely difficult, as it completely overwhelms a person's body, often with little to no notice for the person, and leads to a total loss of control. In the middle of an RSD meltdown, the person may feel intense self-hatred, suicidal ideation, aggression towards those around them (even those that the person didn't initially feel rejected by, they may now direct aggression toward, as a way to assert control) and at time physically violent towards themselves and/or others. Below are some strategies which may be helpful when living with, loving, working, or helping to educate someone who has a strong RSD profile. Hopefully these strategies are also helpful if you are the one who has the strong RSD profile.

With difficult conversations, introduce ways to delay responses – Emotion takes over at times for people with RSD, not allowing their logical brain to respond. When their response is delayed, this gives them time to process the information and plan their response.

Where possible, have difficult conversations over text/email – Communicating through messages can be greatly beneficial for some people with RSD. This is due to them being able to process the emotion & message before responding, they can plan and carefully word their response and are unable to read into body language or tone of voice. It may be easier for people with RSD to have difficult conversations in text messages or Facebook Messenger as this takes away the face-to-face emotion and allows them time to process and think before responding. This enables them the ability to self-talk and remind themselves not to interpret everything as a threat, attack or as ridicule.

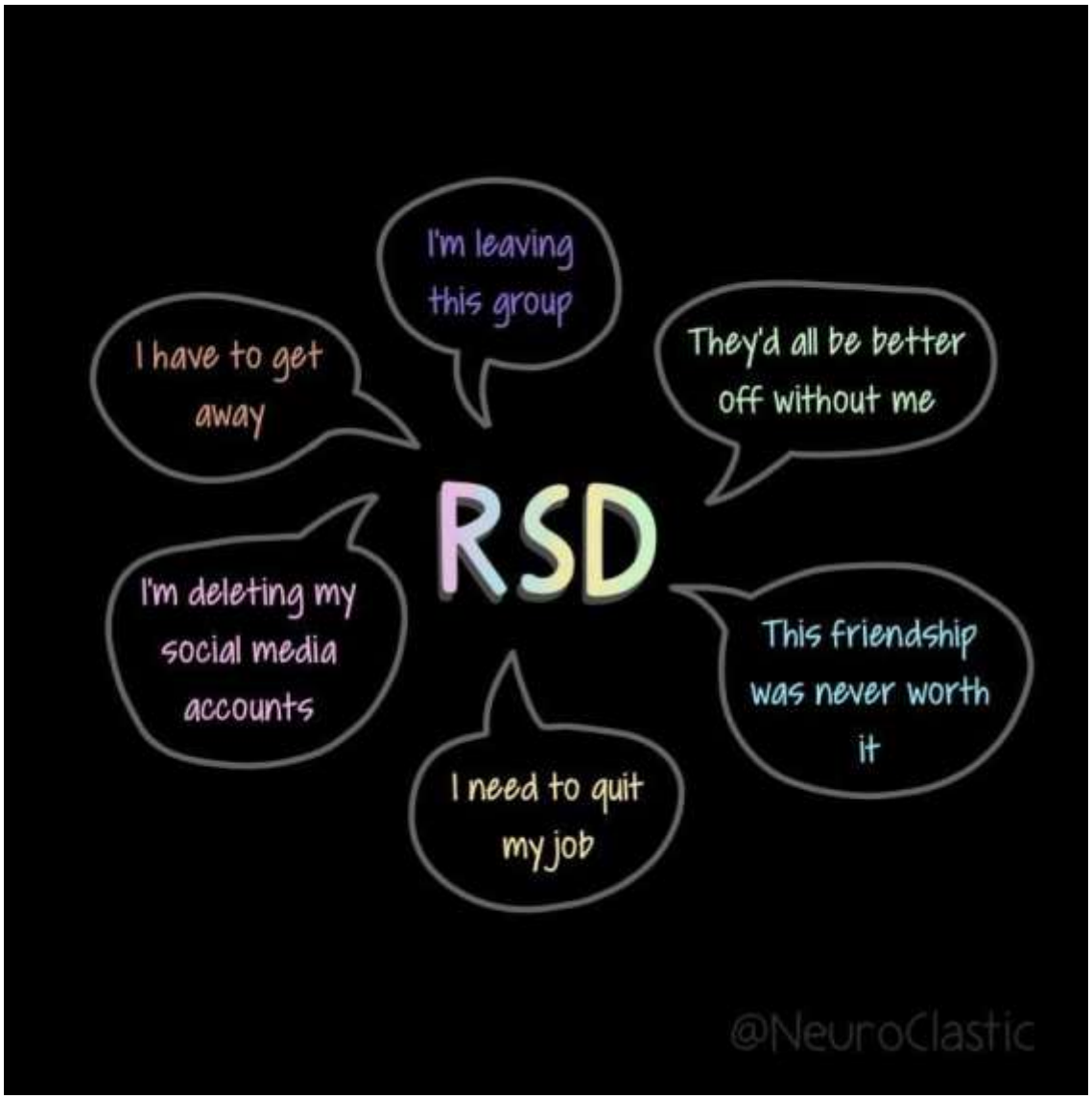
Be as consistent as possible with the amount of excitement and validation that is offered – When a person offers a lot of excitement and validation one day, then the following day is preoccupied and distant, the person with RSD is going to fixate on seeking out the validation and excitement they received the day prior. This can at times result in someone with RSD being obsessed with the person, either attaching themself to the person and wanting more from them or having a passionate hatred of the person as an act of self-preservation to protect themself from the unpredictability.

Provide genuine compliments and praise when truly appropriate – As much as people with RSD seek out validation and compliments, they are also hyperaware of the truth and honesty of the compliments. Don't provide baseless, standard compliments or you will be seen as being fake. Remember true signs of validation, or anything that enables someone to feel like they are successful is a pure dopamine hit to the ADHD brain and is intoxicating, addictive and immensely nourishing. Be careful with praise and compliments as it can be a life source for those with a strong RSD profile.

Don't ever mix praise or compliments with constructive criticism or 'issues' – If even the slightest issue is raised, then the person will not hear or pay attention to any of the praise or compliments also provided. If you need to have difficult conversations, provide constructive feedback, explain something that needs to be corrected or anything else which can be perceived as negative, then plan this carefully. Choose a time when the person is at their best and seems the most resilient. Provide this feedback clearly and minimally, remembering that the person will 'feel' it, or 'take it on' a lot more than their peers who are not RSD, even the slightest correction can be felt like a brutal slap. After this is done, it might be helpful to give it a few minutes, then do something like ask the person for help doing something they are good at or ask them to remind you how to make something that they are better at than you. Any way at all to remind them of the things that they are best at, is the best way to help their brain get out of the self-loathing spiral they may be in and back to more constructive and positive thoughts.

Offer overwhelming amounts of love and warmth after a meltdown – Remember those with RSD profiles need a lot more love, warmth, and emotional validation than those who don't have RSD. After the person has had a meltdown / experienced distress, make sure you take extra steps to remind them how much they are appreciated (if not family), or loved and wanted (if family). Just saying it's ok or just agreeing

to move on is not enough. The person will need a lot more emotional evidence that things are OK again and may seem uncertain for quite a period of time afterwards.



Take the time to explain what you mean and be mindful that the person is looking for evidence that they have stuffed things up – Communication with someone with a strong RSD profile should be considered (planned) and come from a place of affirmation, not condemnation. Highlight the positives more than you normally would and minimise the negatives more than you normally would. Any sign of rejection or blame will be amplified by the person with the strong RSD profile.

Verbal De-Escalation Techniques for Defusing or Talking Down an Explosive Situation

Author: Eva Skolnik-Acker, LICSW; Committee for the Study and Prevention of Violence Against Social Workers, National Association of Social Workers, Massachusetts Chapters:

When a potentially verbally and/or physically explosive situation occurs, verbal de-escalation is needed. There are two important concepts to keep in mind:

1. Reasoning logically with a very angry person is not possible. The first and only objective in de-escalation is to reduce the level of anger so that discussion becomes possible.
2. De-escalation techniques do not come naturally. We are driven to fight, flight or freeze when confronted by a very angry person. However, in de-escalation, we can do none of these. We must appear centred and calm. Therefore, these techniques must be practiced before they are needed so that they can become "second nature."

There are 3 parts to be mastered in verbal de-escalation:

A: THE PERSON IN CONTROL OF HIM/HERSELF

- Appear calm, centred and self-assured even though you don't feel it. Relax facial muscles and look confident. Anxiety can make the client feel anxious and unsafe which can escalate aggression.
- . Use a modulated, low monotonous tone of voice (our normal tendency is to have a high pitched, tight voice when scared).

- If you have time, remove necktie, scarf, hanging jewellery, religious or political symbols before you see the person (not in front of him/her)
- Do not be defensive-even if the comments or insults are directed at you, they are not about you. Do not defend yourself or anyone else from insults, curses, or misconceptions about their roles.
- Be aware of any resources available for back up and crisis response procedures.
- Be very respectful even when firmly setting limits or calling for help. The agitated individual is very sensitive to feeling shamed and disrespected. We want him/her to know that it is not necessary to show us that they must be respected. We automatically treat them with dignity and respect.

B: THE PHYSICAL STANCE

- Never turn your back for any reason
- Always be at the same eye level. Encourage the person to be seated, but if he/she needs to stand, you stand up also.
- Allow extra physical space between you – about four times your usual distance. Anger and agitation fill the extra space between you and the person.
- Do not stand full front to person. Stand at an angle so you can sidestep away if needed.
- . Do not maintain constant eye contact. Allow the person to break his/her gaze and look away.
- Do not point or shake your finger.
- DO NOT smile. This could look like mockery or anxiety
- Do not touch – even if some touching is generally culturally appropriate and usual in your setting. Very angry people may misinterpret physical contact as hostile or threatening.

- Keep hands out of your pockets, up and available to protect yourself. It also demonstrates non-verbal ally.
- Do not argue or try to convince, give choices i.e., empower.
- Don't be defensive or judgmental.

C: THE DE-ESCALATION DISCUSSION

- Remember that there is no content except trying to calmly bring the level of anger down to a safer place.
- Do not get loud or try to yell over a screaming person. Wait until he/she takes a breath; then talk. Speak calmly at an average volume.
- Respond selectively; answer all informational questions no matter how rudely asked, e.g. "Why do I have to do this g-d homework?" This is a real information seeking question). DO NOT answer abusive questions (e.g., "Why are all teachers (an insult?) This question should get no response whatsoever.
- Explain limits and rules in an authoritative, firm, but always respectful tone. Give choices where possible in which both alternatives are safe ones (e.g., Would you like to continue our discussion calmly or would you prefer to stop now and talk tomorrow when things can be more relaxed?)
- . Empathize with feelings but not with the behaviour (e.g., "I understand that you have every right to feel angry, but it is not okay for you to treat myself or others this way.)
- Do not solicit how a person is feeling or interpret feelings in an analytic way.
- Do not argue or try to convince.
- Wherever possible, tap into the person's thinking mode: DO NOT ask "Tell me how you feel. But: Help me to understand what you are saying to me" People are not attacking you while they are teaching you what they want you to know.
- Suggest alternative behaviours where appropriate e.g., "Would you like to take a break and have a cup of water?
- Give the consequences of inappropriate behaviour without threats or anger.
- Represent external controls as institutional rather than personal.
- Trust your instincts. If you assess or feel that de-escalation is not working, STOP! You will know within 2 or 3 minutes if it's beginning to work. Seek help and follow crisis response plan.

There is nothing magic about calming a very angry or agitated person. You are transferring your sense of genuine interest in what the person wants to tell you, of calmness, and of respectful, clear limit setting in the hope that the person wishes to respond positively to your respectful attention.

Fanciful Distraction

Sometimes it's necessary to use fanciful and imaginative methods of distraction to help people out of potentially dangerous, self-harming or distressing behaviour. Fanciful distraction is the term applied to:

'Distracting someone with a make-believe stimulus as an urgent method of changing their focus'.

The concept behind fanciful distraction is to provide something fairly dramatic to focus on to *rapidly distract the person from whatever they are focused on.* This is different to normal types of distraction-based strategies as the concept or idea you are using must be a bit dramatic in order to be effective. Fanciful distraction must be used carefully as we don't want to create habits of lying to those we work with or doing anything which could be considered exploitative of their trust. However, in many situations, we have to weigh the risk with the benefit when making ethical determinations about strategies. In situations when fanciful distraction is appropriate, the risk is usually significant.

Fanciful distraction can be used in some of the following instances:

- A person is about to hurt someone else.
- A person is extremely distressed about something and becoming more and more distressed without signs of self-soothing.
- A person is struggling with reality and/or very confused about something which might have happened.
- A person just had something happen to them that they don't understand and that is causing them distress.

- A person might be stuck in a repetitive loop of thinking and not able to pull themselves out of it.
- You're driving and the person becomes upset and (based on their historical presentation) is about to become aggressive and place themselves and others in the vehicle at risk.
- The person has an assessed high risk of behaviour and is at risk of doing harm to themselves or others as a result of the way they respond to situations.
- The person has a history of problematic mental health (which can lead to risk of harm) and becomes fixated on ideas without the skills to move on from them.

Fanciful distraction can:

- Provide enough time for the person affected to lose the angry/distressed energy they had and have some capacity to see with more clarity.

- To stop thinking about whatever it was which was consuming them and distressing them.
- To immediately stop a chain/pattern of behaviour which was likely to end in harm to the person or someone else.
- Provide some perspective and some time away from toxic and hurtful thoughts.

How do you use fanciful distraction?

It's helpful to have some ideas already which will suit the person you're working with. The ideas must be:

- Relevant to the person.
- Interesting enough to work as a distraction.
- Dramatic enough to take the person out of the frame of mind they were in.
- Able to be executed (eg. Played out) by you, or whoever is using them, in such a way that they are believable.
- They cannot be something that unfairly affects the person later (eg. Saying mum is visiting when she is not, then getting the person excited – this is NOT ok).
- They cannot be something that you cannot prove later or you will lose the trust of the person (eg. Distractions about cars you saw, which are already gone are great, but saying something is going to happen tomorrow when it's not, is actually setting the person up for failure and is NOT ok).
- This cannot be something that other people have to play into and/or something that carries on beyond the time you spend with the person (eg. Don't start a web of lies or anything that requires other workers to be involved. Don't say things like "Your worker Jack is really sick", then have Jack turn up perfectly well).
- Fanciful distractions should be short, fleeting distractions which are dramatic in nature and over quickly.

Some examples of fanciful distractions which might work are:

- "Oh my, did you just see that plane in the sky – was it carrying another plane somehow?"
- "Oh gosh look, is that an animal on the side of the road over there?"
- "Hang on a second, I think I just heard a helicopter flying over us, can you hear it?"
- "Oh gee, hang on, I feel really sick, Oh gosh, I think I'm going to be sick , we need to pull the car over for a second"
- "Holy Dooley, is that red car out there a Porsche?"

- “Oh gosh, is that your phone ringing?”
- “Hang on, I thought I just heard them call our number – was that them? Should we check?”

As you will see from the above examples, using this strategy shouldn’t affect the trust the person has with you as the distractions are fleeting and can be explained away (“oh, maybe it wasn’t a helicopter”, “oh no, it’s not a Porsche, just a Hyundai – goodness I’m dopey today” etc).

Fanciful distractions will hopefully help provide some space for the person from the thoughts they were having, which was leading them or others to a situation of risk or harm. Please use this technique very carefully and with guidance from your Specialist Behaviour Practitioner or Therapy Assistant as it’s important that it’s not used in such a way that can lead to the person losing trust in their workers, or in such a way that creates webs of lies or deceit. Fanciful distraction should be short, swift, not able to be proven incorrect and not requiring the investment or ‘buy-in’ of anyone else.

Tone and Reality Policing

Tone Policing: Telling someone how emotional they should be and making them feel like they need to change the tone of their expression.

Reality Policing: Telling someone what is and isn't true and correcting them about things they say which may not be true.

Gaslighting: To undermine a person's reality by denying the facts and saying things to manipulate their perceptions, by sowing seeds of doubt.

Tone and reality policing is generally not a helpful, nor appropriate thing to do when working with vulnerable people and can sometimes be argued to be similar to gaslighting. Tone policing includes telling people they should be calmer in their communication and not worry about certain things. Reality policing is where you find yourself constantly correcting people who might be confused, have mental illness or intellectual impairment, or just not understand something yet.

How do I know if I am Tone Policing?

You may already be guilty of tone policing (many of us are) in your personal or work life. If you have found yourself saying any of the following to people you work with, it might be time to stop and self-reflect.

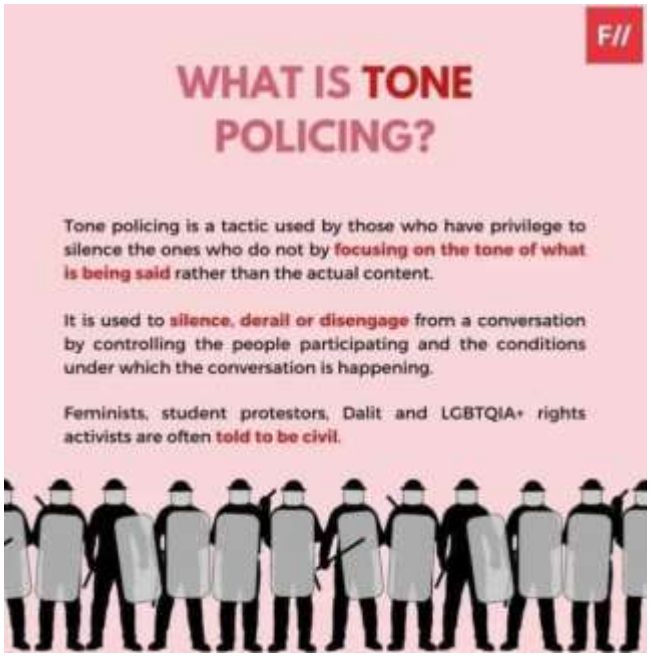
- *"It's not that big a deal."*
- *"Calm down."*
- *"You're worrying too much, it doesn't concern you."*
- *"Stop being so upset."*
- *"Don't talk to me with that tone."*
- *"You're being so worked up about this."*

- *"It's not that bad."*
- *"You need to relax."*
- *"Don't worry – it's not your issue."*
- *"You're overreacting."*

Making comments such as the above is telling the person that their thoughts and feelings are incorrect and that they should not feel how they do. This can make people feel like they are doing something wrong and feel detached from their feelings.

We actually have NO right to tell people what they should or shouldn't be feeling. Instead of saying things like *"don't be so upset*", we could say *"why do you think you feel so upset about that?".* This change allows the person an opportunity to unpack and explore their feelings, rather than being made to feel that their feelings are wrong.

Further to this, tone-policing is both patronising and condescending. There isn't a supreme authority which exists to determine appropriate amounts of emotional expression, yet tone policing infers there is. This makes people feel devalued, disengaged, silenced, silly, wrong and juvenile.



Reality Policing

Reality policing is when people feel the need to correct people on the basis of 'what is actually true and correct' and what is not. It's not uncommon for a person with a mental illness or disability to have altered views of the world or

believe things which may not exist. In some situations, magical alternate worlds are developed by people with dialogues and narratives which suit them and provide comfort. Some people repeat sections of television shows or movies as if it's happening right in the present. This can be done due to how comforting the repetition is, or because they enjoyed the part of the show and are re-acting it out again. There are a variety of alternative realities for people and it's not our duty to walk around as the providers of truth and accuracy. In many situations, being part of the alternate reality provides significant comfort and can be a source of fun and enjoyment.

The only times that reality policing, or pushing the truth is acceptable is at times of risk, or due to some other source of specialist advice. As an example, if the person is very depressed and making comments that everyone hates them, then (even if this looked correct) you certainly wouldn't agree with it and go along with it. Further to this, if the person is getting super excited, saying that their mother is coming to visit and you know that this isn't true, then it's not helpful to go along with it. In this instance, it's better to ask questions such as *"What makes you think mum is coming over today, did she tell you?"* and help them to see that it's not happening.

Example of reality policing

Client *"When my money comes in later this week, I'll have more money than anyone in my bank."*
Worker *"No you won't Julie, it will be good that your money is in there, but lots of people have more money."*
Client *"No they don't, my money will make me richer than anyone."*
Worker *"Julie, that's not true. You're just lying now."*

Example of NOT reality policing

Client *"When my money comes in later this week, I'll have more money than anyone in my bank."*
Worker *"Goodness gracious, that's a lot of money then!"*
Client *"Yep. It's going to make me so rich, I'm so excited"*

Worker *"Well, I hope you've got some great ideas about how to save it, so you can stay being so rich."*

There's not benefit, nor need to tell Julie that she's not going to be the richest person in the world. It's ridiculous to think that workers feel the need to frequently do this. It doesn't hurt for people to be excited and have a loose grasp of reality. Reality can be very boring and it makes sense that so many of us need to dream a bit more than others.

Example of reality policing

Note: Jack is the therapist who provides speech therapy to the client and is in no way connected to the worker (e.g. Not in a relationship, the client is just confused)

Client *"Jack is your husband"*

Worker *"No, Jack is your Speech Therapist, not my husband, that's not true."*

Client *"Yes HE IS, Jack IS your husband."*

Worker *"Stop saying that, Jack is not my husband at all."*

Example of NOT reality policing

Client *"Jack is your husband."*

Worker *"What? *laughs* what makes you think he's my husband? Remember I don't have a husband, Jack is just your Speech Therapist."*

Client *"Yes HE IS, Jack IS your husband"*

Worker *"Well, ok then… that's what you keep telling me… *laughs* Goodness me, I can't keep up with all these people I'm marrying."*

The above scenario is not an uncommon one. Many clients form strong bonds with their therapists and support workers and can become confused in the difference between family, relationships, therapists, workers etc. Sometimes this can lead to clients calling people their husband, or mother, or expecting workers are family or partners. It's perfectly fine to correct the person casually, but if the client is being insistent and pushing the point, then it really doesn't matter – does it?

Workers sometimes get very hung up on the truth and have the attitude that 'if we don't correct the person, then they will believe this' – this is not the case. Sure, don't make it

worse, but make it silly instead. In the above example the comment *"I can't keep up with all these people I'm marrying"* is a handy one to remind the person that it's a bit of fun.
Don't get hung up on reality, it can really be quite boring, much of the time ☺

Trauma Based Disorders

Post-Traumatic Stress Disorder (PTSD) and Complex Post-Traumatic Stress Disorder (C-PTSD): This is the most well-known of the trauma-based disorders and can occur after a person experiences a situation of trauma. The difference between PTSD and C-PTSD is that C-PTSD exists after prolonged trauma, such as childhood abuse, whereas PTSD can exist after once off traumatic incidents, such as car crashes or assaults. Any trauma-based disorder can effectively change how the brain processes information and can lead to the brain blocking certain information totally. This could include avoidance of anything that reminds the person, or could be considered linked to the trauma, as well as feelings of being unsettled and dysregulated, intrusive thoughts and flashbacks and fears and paranoia.

C-PTSD often results in long-term changes to the person's behaviour, coping strategies and mental health. Many with C-PTSD will have a very negative self-view that they are constantly trying to ignore, or conversely, constantly trying to be validated for. With some, the acknowledgement from others of how unwell they are can be immensely validating and for some, this acknowledgement can be extremely intrusive and unwelcome.

When having a psychotic episode linked to trauma (e.g., This means when the person is extremely distressed and escalated), the person can appear to be detached from reality and be talking about things that are not there and talking to and about people who aren't present. Psychotic episodes for some people can last for a day, or several weeks. When experiencing a psychotic episode, the person's behaviour is very different and standard strategies to respond are often totally ineffective. During psychotic episodes, the person may actually believe that things are happening to them, or they

are still experiencing this, or similar trauma. Reports have stated that during an episode, the lines of reality are not only blurred, but unable to be seen by the person at the time.

Reactive Attachment Disorder (RAD): This exists when children are unable to form attachment with their care givers. It's most likely present in children who have been abused or neglected by those who were meant to look after them. This presents as emotional withdrawal, lack of responsiveness when others are providing comfort. It's also common that those who have RAD will have excessive or unpredictable sadness, irritability, fearfulness, or anger.

Disinhibited Social Engagement Disorder (DSED): Although similar in cause to RAD, DSED exists in situations where children do not know how to form appropriate and culturally normal relationships with others. Examples might be when children are over-friendly with others, such as sitting on the laps of strangers or trying to be part of private conversations. There is significant risk in children who present with this as they exhibit no fear of strangers and no understanding of the signs of dangerous behaviour from adults.

Personality Disorders Commonly linked to being the result of childhood abuse and trauma

Borderline Personality Disorder (BPD): Borderline Personality Disorder affects 2-6% of Australians and presents as intense emotional feelings that are difficult to manage. Statistics indicate that most people with BPD have endured childhood abuse and/or significant trauma as a child. It is very likely that those with BPD will self-harm and struggle with substances like alcohol and drugs, as well as food. People with BPD are often very impulsive, can feel quite empty and struggle to understand their identity. Many individuals with BPD need to feel 'sick' and 'significantly affected' in order to feel validated as a person. Often, if people around them are sicker, or have more significant issues, the person with BPD feels invalidated and can feel even more sad and unwell. Often, it's necessary to help the person with BPD have a regular source of emotional expression to meet their needs and avoid the more dramatic feelings which can lead to self-injury. After experiencing happy or joyous moments, a person

with BPD can sometimes experience more significant depressive episodes, as the happier they have been, the more empty they will then feel as a result.

It's very likely that people with BPD form relationships with others very quickly and often without the usual caution demonstrated by their non-BPD peers. The person with BPD can take any courtesy as emotional nourishment and misunderstand normal kindness provided by others. It's very important to be aware of the need for emotional attachment when working with people BPD as rejection can be extremely traumatic and lead to serious and debilitating mental health unwellness. There is a high degree of emotional manipulation demonstrated by many people with BPD. This is done without realisation in most circumstances as the person is just trying to make you see how unwell they are and how much they need your help, without always realising that their behaviour of harming themselves when they don't feel supported or acknowledged enough is very manipulative to those around them.

Just like any mental illness, personality disorders such as this have varying levels associated with presentation. The above description is based on standardised presentation only and is not indicative of all those with NDP, nor is it designed to be used in any kind of diagnostic capacity. Diagnosis of a personality disorder can only be done by a psychiatrist after testing and assessment.

Narcissistic Personality Disorder (NPD): NPD is not like what we see in the movies, where a person performs evil acts for fun or to get their own way, people with NPD are survivors of trauma whose brains have created a set of coping skills to manage life and manipulation is

often a way to create a feeling of safety. Many would describe NPD to be almost the opposite of BPD but coming from the same place and as a result often, of childhood abuse, neglect and/or trauma. The person with BPD (as explained above) often needs to 'feel sick' to feel validated, whereas the person with NPD sees illness as serious weakness and avoids any acknowledgement of this where possible. People with NPD are often confident in certain (or all) areas of their lives and will need validation of their skills and abilities from their peers a lot more than others would. The person with NPD often tries to control the narrative by creating stories for others to believe, to make sure other people view things the same way that they do. Being right is very important to people with NPD and the truth is much less important than gaining respect and acknowledgement.

When challenged or if anyone infers the person with NPD is not a 'good person', or 'wrong', it's very likely that the person will respond to this with significant escalation and aggression. There is a high degree of emotional manipulation demonstrated by many with NPD, often as a method of controlling the attitudes of all those around them. It's not unusual for a person with NPD to use threats, intimidation or trying to make others feel guilty, as a method of controlling those around them.

Just like any mental illness, personality disorders such as this have varying levels associated with presentation. The above description is based on standardised presentation only and is not indicative of all those with NDP, nor is it designed to be used in any kind of diagnostic capacity. Diagnosis of a personality disorder can only be done by a Psychiatrist after testing and assessment.

Working with someone who has a Trauma-Based Disorder

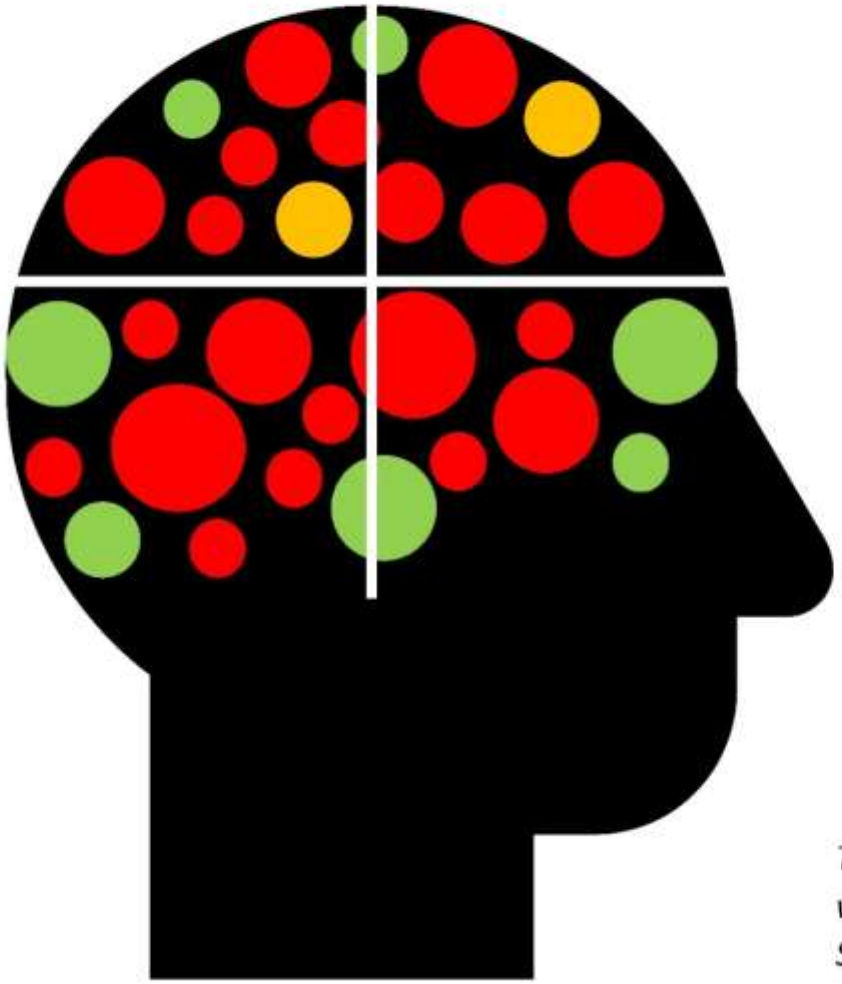
Working with someone who has a trauma-based disorder can be very complex and emotionally exhausting. People who've experienced trauma can have dramatic emotional fluctuations and require much more emotional validation than those without. This can be very difficult for workers as it can be quite taxing emotionally. Some key concepts to remember when working with people with trauma-based disorders.

- Reality wasn't easy for them. Their lives had some very difficult times, and the human brain can only endure so much. In order to cope with this, they often try to change reality and/or create new distractions to focus on. Let this be, this is a coping mechanism.
- They don't need people telling them they are incorrect or constantly trying to be the 'reality police'. Often new realities are necessary to manage the difficulty of how the world is for them and an important coping strategy.
- If they are demonstrating extreme behaviour, then they are likely to be dysregulated. This can happen if there's issues with medication, or there's been a reminder of something traumatic, or if they aren't getting their needs met. Feeling dysregulated is the same as feeling like you've forgotten something and you can't remember what it is, but it's really important. It feels unsettled and you often feel confused as a result. A dysregulated person is likely to have erratic behaviour.
- Distraction is often a much better response to issues than talking about the traumatic topic. Discussing serious issues related to traumatic history is best done by a trained practitioner due to the possibility of re-traumatising someone or affecting their coping strategies by how others respond to their stories.
- People with trauma-based disorders need to feel safe and to feel safe, they need to check people are able to be trusted. It's very common for people with trauma-based disorders to test those around them to see if they will stay with them, or if they are likely to abandon. This can mean that new workers endure some difficult shifts when they first start as the person is pushing them to see if they are strong enough.
- Telling someone who's lived through a trauma-based disorder that they are over-reacting to something is effectively gaslighting them. No-one has the right to dictate

what a reasonable emotional response is and it's not the role of workers to tell people that they have responded incorrectly, or too much to something.

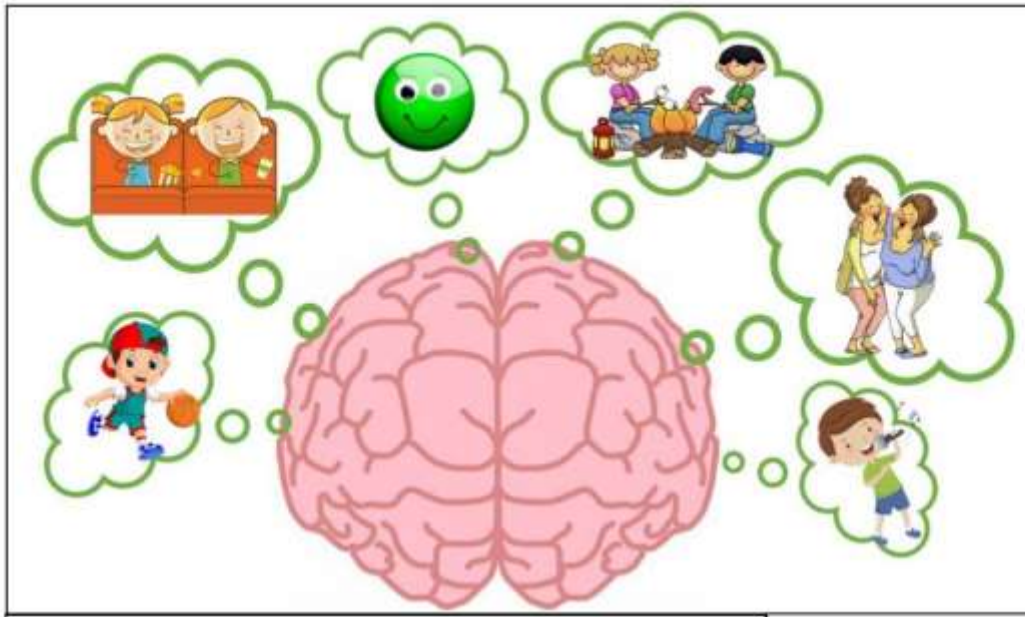
- It's essential to find out what source and type of validation and support the person needs when working with them as they will not be regulated if they don't receive this. If a person needs to have their ego inflated (eg. A person with NPD), then please do this as without this, the person will not feel comfortable and regulated). If a person needs to know that you understand how sick they really are, then it's important to provide them this validation or they are likely to do what is needed to really show you how sick they feel they are. Validating the needs of someone is essential.
- Anxiety is a huge issue for most people with trauma-based disorders. Anxiety can occur due to uncertainty about what's happening, or feelings of not being in control, hypervigilance or just not feeling like you're coping. Anxiety often happens when people are not regulated as well

The Brain, Faulty Neuroception and What WE Can Do!



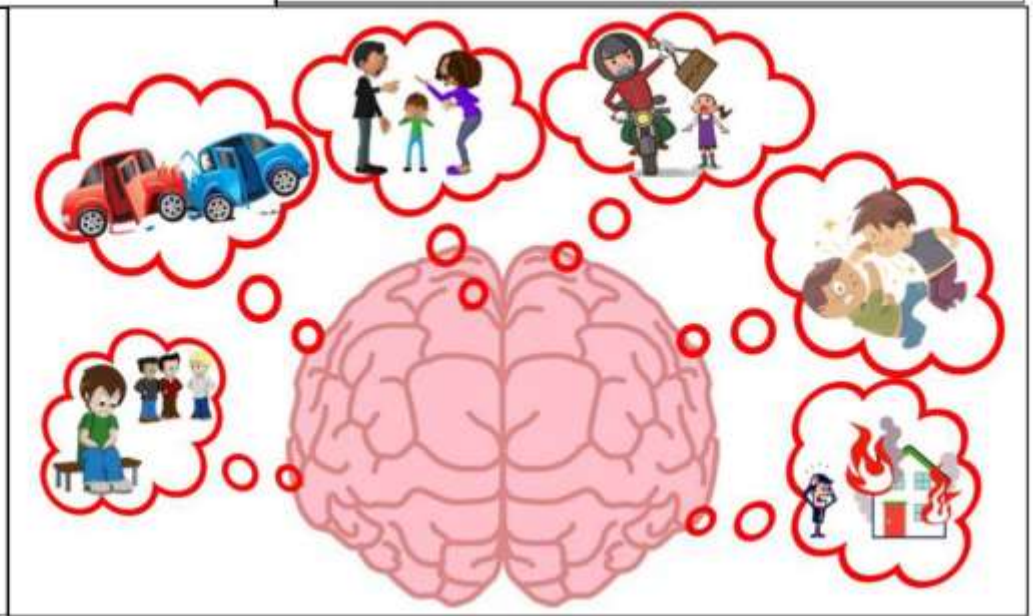
Some strategies and steps to help respond to those whose brain is protecting them a little bit too much and stopping them from thriving in life.

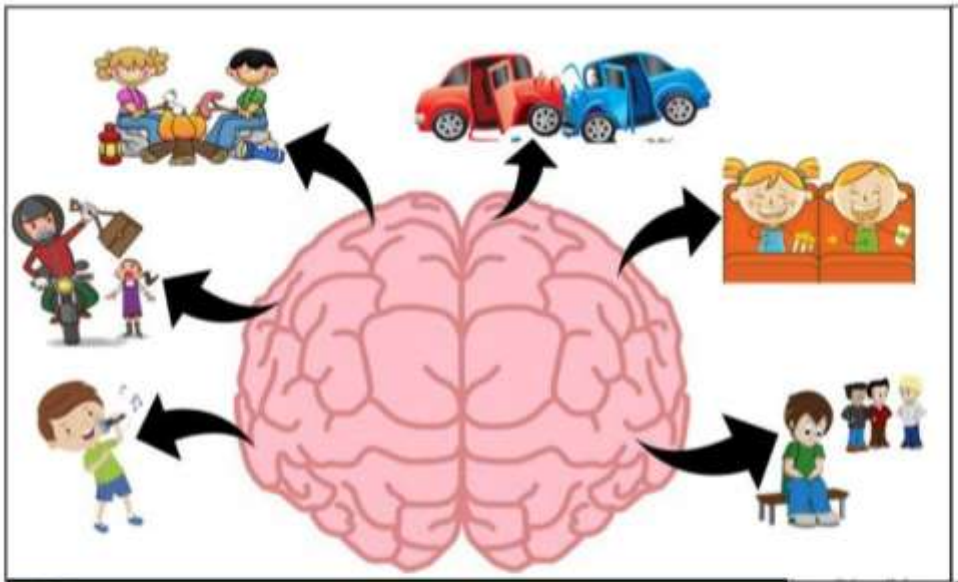
This little story is created by Instinct CBT and based on the work and teachings of Mona Delahooke PhD and Dr Dan Siegel.



Positive neural connections are formed when we have good experiences and form great memories.

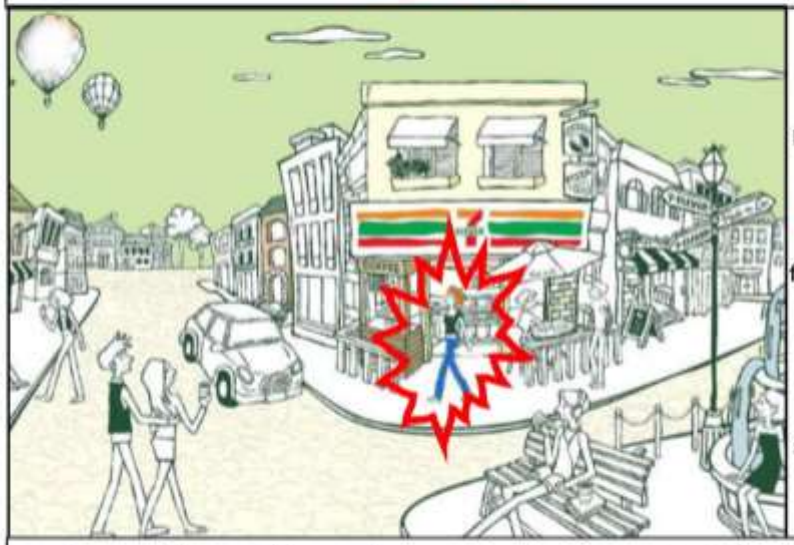
Negative neural connections are formed when we have bad experiences. Our brain connects these bad experiences to things that our brain thinks are responsible for or linked to those bad experiences. When we see or experience things after these neural connections are formed, it makes us feel a certain way.





Neural connections are essentially memories in our brain. Some memories we can share, and recall (explicit memories) and some memories are formed without us realising (implicit memories).

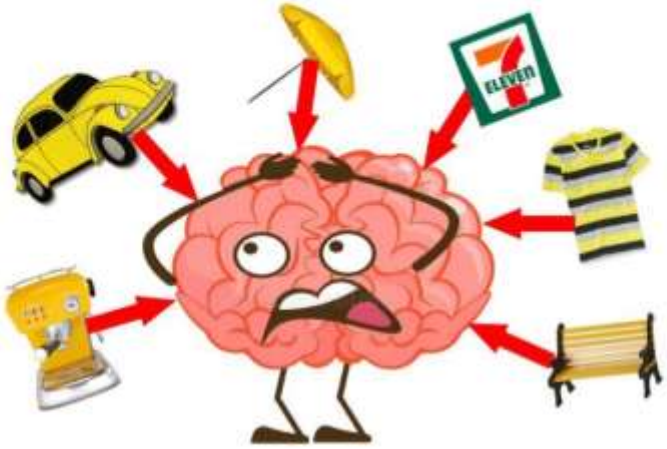
We often don't know about implicit memories until something triggers us. Like, when we hear a song, and it makes us feel sad and then we realise that the song was played at the funeral of a friend.



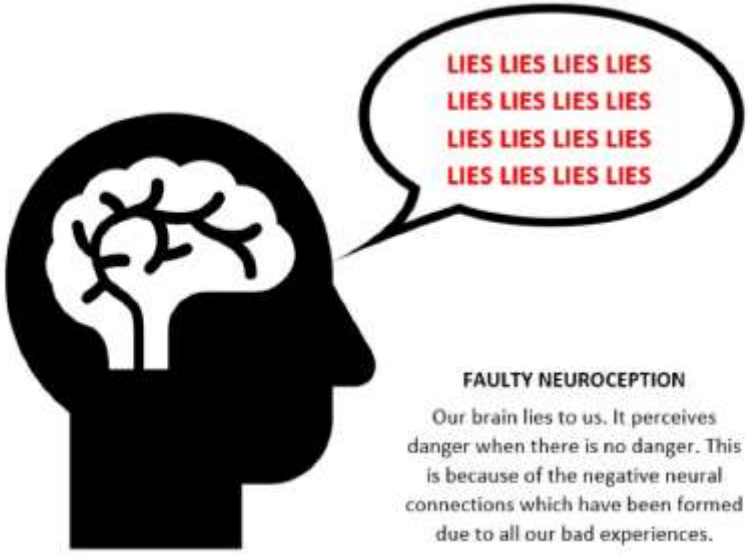
If someone physically attacks you outside a 7-Eleven, that would be a highly **traumatic** event. Your brain links feelings of fear and terror to random items, people, tones of voice, inanimate structures, sounds or even visual images.

Any of these things in your environment at the time could become negative explicit or implicit memories, as a result of the way the brain makes neural connections.

Now 7-Eleven stores, certain cars, striped shirts, umbrellas or shop front coffee machines might make you feel fearful because of the neural connections formed. It is likely that neural connections form as a way for your brain to protect your body from ever having to experience an attack again. This is your brain saying "*hey, this feels or looks like that bad thing that happened, run away, fight, hide or escape!!*"



As we go through life, if we have lots of bad experiences, we can end up forming lots of negative neural connections which link everyday items and people to feelings of trauma, fear, anger, betrayal and sadness.



FAULTY NEUROCEPTION

Our brain lies to us. It perceives danger when there is no danger. This is because of the negative neural connections which have been formed due to all our bad experiences.

When we are fearful, or scared, we operate from our lower brain and cannot access our upper brain.

NEURAL CONNECTIONS AT SCHOOL

Just like the scenario at 7 eleven, children can form negative neural connections regarding many things in the school environment.

Some children might have negative neural connections about answering questions, being spoken to by the Teacher, children taking things from them, being asked to share their property, being told to pack up their things or being asked to come back inside after lunch.

This might make these children respond in their lower brain instantly when any of these things happen. These negative neural connections can be formed as a result of the numerous times their brain experienced fear, hurt, rejection or sadness and didn't have a logical reason which helped them still feel safe. This will result in the child having **FAULTY NEUROCEPTION**. Their brain will start believing there is danger, even when there's not.

REMEMBER...

Our instinct and reactive response, including fight, flight, fear, anger, and heavy emotional expressions live in our lower brain. Our problem-solving, critical reflection, thoughtfulness, logic, forethought, and cleverness all live in our upper brain. Our upper brains aren't fully developed until we are in our 20's.

The lower brain is pretty cheeky and when it's being used, **it locks us out of our upper brain!** This means, when we are in fight, flight, instinct, or reactive response mode (responding to crisis), we cannot use cleverness, or problem solving. We act on instinct and impulse alone.

If our instinct is based on a lot of negative neural connections, then this might be very problematic ☹

Faulty Neuroception

Faulty neuroception happens when our brain has formed too many negative neural connections. This makes our brain believe that heaps of things in our normal environment pose danger to us!

This means we go into fight, flight, anger and instinctive response mode and try to protect ourselves, even when we don't need to.

If we have lived through lots of bad, scary or fearful experiences, then our brain becomes filled with negative neural connections.

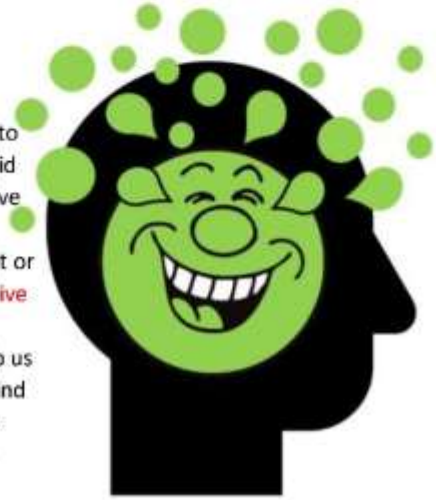
This will mean we will be frequently triggered to use our lower brain.

● = Positive neural connections and memories

● = Negative neural connections and memories

HOW DO WE RESPOND TO FAULTY NEUROCEPTION?

1. We need to make more positive neural connections!
2. We might need help from someone else to co-regulate. This means they help us avoid situations that could lead to more negative neural connections.
3. We need to talk about things which upset or bother us to avoid them becoming negative neural connections. We can do this by talking through difficult situations to help us understand why things happened & remind us that we are still safe. This then makes these experiences into opportunities for learning which sit in our upper brain.



Making positive neural connections is not achieved by just 'doing' or 'experiencing' things. We must discuss our experiences to make them memories, or they disappear into our brains, or get overpowered by negative neural connections. Actions or discussions transform fleeting thoughts into helpful memories which take up space in our brain.

We can never eliminate all of the negative neural connections (red balls) however, we can create a majority of positive neural connections (green balls).

If we have a lot of positive neural connections, our brains won't kickstart our fight, flight, instinct and anger response (lower brain) so readily.

FAULTY NEUROCEPTION & CHILDREN

Some children's brains are filled with negative neural connections. This could be from overwhelming sensory experiences, feelings of being attacked, bullied, punished, disliked, or feelings of failure.

Those children will go into fight, flight, anger mode (lower brain) instantly. Children operating from the lower brain cannot problem-solve, nor use logic or reasoning.

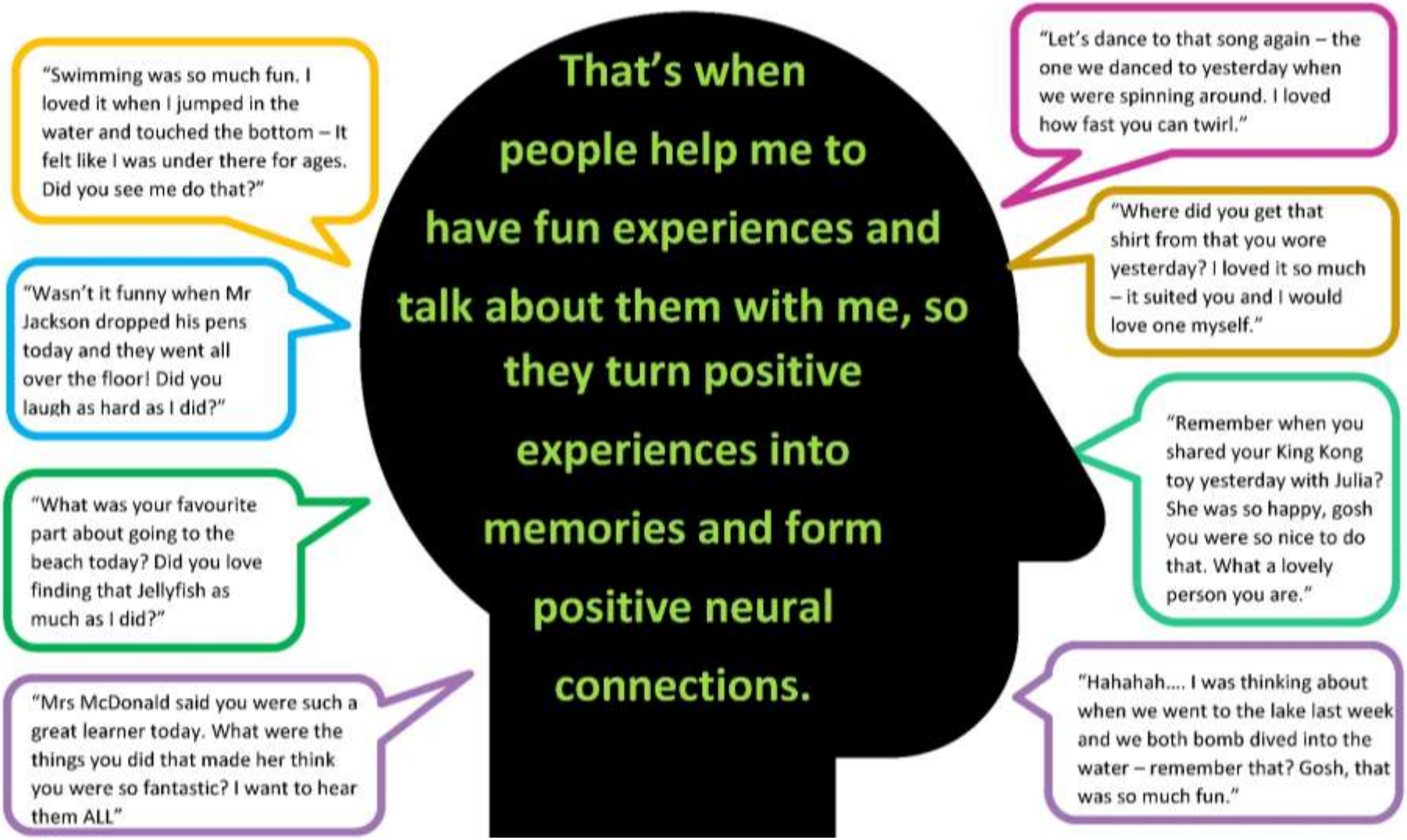
If a child can't access their upper brain, they cannot learn. We don't learn when we are in our lower brain.

How do we help a child learn if the child is constantly **surrounded** by all of these triggers, in their classroom and school?

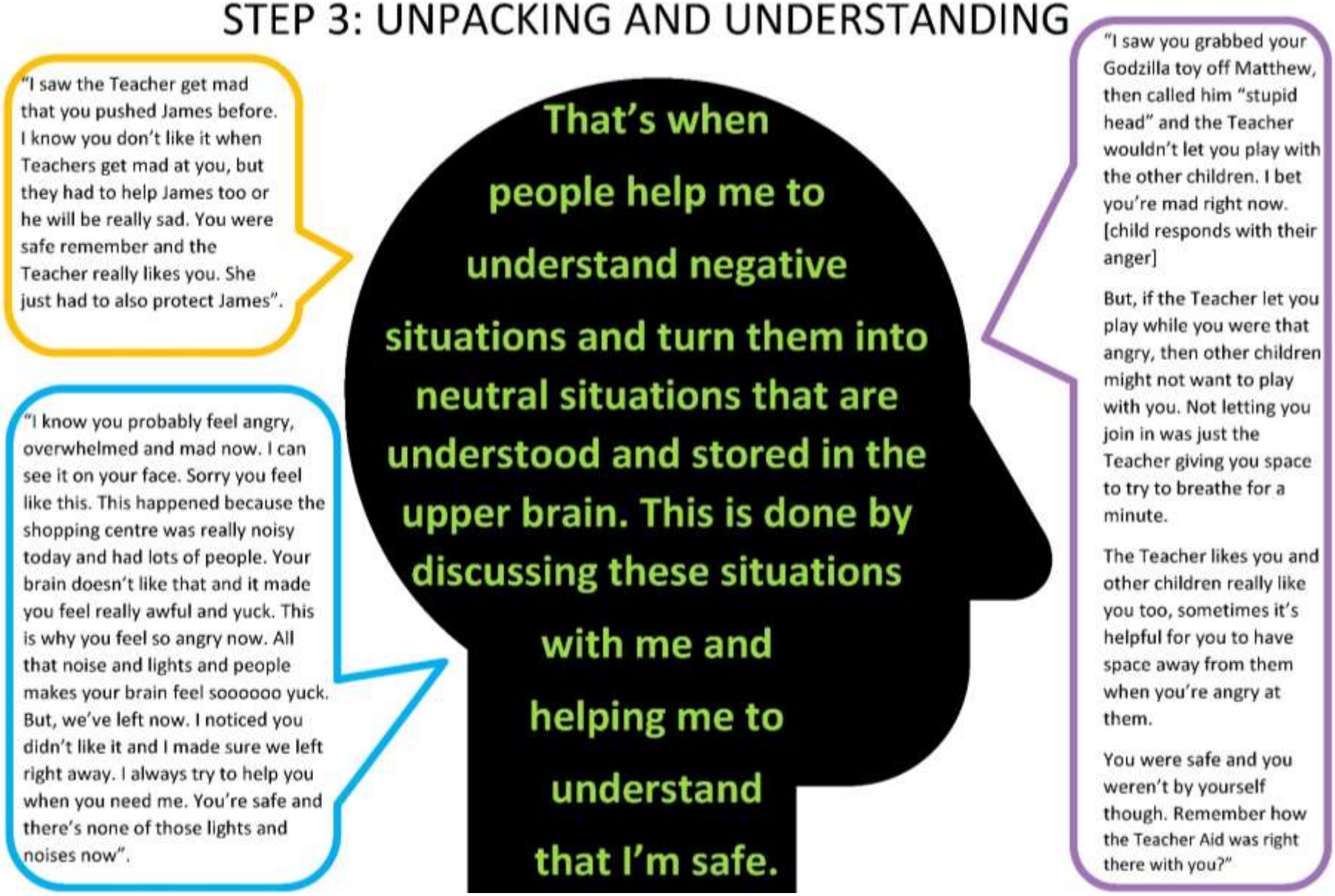
Follow the next three steps...

STEP 1: CO-REGULATION

STEP 2: CREATING POSITIVE NEURAL CONNECTIONS & MEMORIES



STEP 3: UNPACKING AND UNDERSTANDING



The Danger of Reward and Sticker Charts

Reward systems (internally created or society driven) are one of the most dangerous things for the ND brain, especially ADHD brain. As a neurodivergent person who's been personally adversely affected by reward systems, I've written this to explain the way my ADHD brain is affected by them. This is written hopefully with the intention that others are educated and can help children avoid this danger.

For people like me, I MUST achieve, no matter what - there is no consideration of failure, and I will suppress any other need I have and push my brain further than it's been before.

Achievement and the need to meet all expectations is consuming.

This need for achievement in the ADHD brain is called Reward Deficiency Syndrome. It's not something which is very well-known and yet every ADHD'er experiences it to some extent. I am driven for reward and rewards give me an awesome hit of dopamine in my brain. Rewards make my brain go into overdrive - to a place which is unsustainable outside of the reward focus. I am at a point now where I have pushed my brain so far, due to me using achievement as a dopamine-inducing reward system, that I cannot even socialise outside of work. My brain cannot manage situations without this dopamine source (achievement / reward) due to how far I've pushed my brain over the years. If a conversation lacks what I perceive as purpose or necessity, I cannot make myself have it / be part of it. Work for me is the best dopamine hit and I'm addicted to the rewards it continually provides.

For kids, with school rewards such as star charts, they (children) push their little brains so far to achieve or demonstrate the behaviour which will gain the reward, then they come home and are unable to manage their excessive brain energy they've created with their intense drive and focus. One of my little ppl has removed his fingernails and toenails this week due to losing one of the stars on this chart and not being able to manage the anxiety over this massive hyperfocus being unsuccessful. Loss like this to the 2E (twice exceptional) brain is insurmountable and way more than what the brain can achieve.

Then there is the other side…

For children who lack the skills to achieve the reward, the presence of reward doesn't automatically teach them the skills they need.

If you set up a reward system which required me to do calculus to get the reward, I would know immediately this was unachievable and know I was definitely going to fail.

This would cause either feelings of loss and failure, or the more likely ADHD-driven need to make a big deal and **"fail epically".** I would disrupt everyone trying to achieve the reward, making sure they all saw how bad and irrelevant it was (because I can't do it) and would go out with a bang.

Reward systems infer that children have the skills to be well behaved **but have chosen not to** and therefore the notion of reward will drive them to suddenly behave. Yet, why would a child choose not to behave? Do any of us choose not to behave when we know how to behave?

Children do well and behave when they can. Children who aren't behaving are like this because they actually lack the skills to do so. They need to be taught these skills.

Reward systems only highlight their lack of skills in a certain area and shame them.

Reward systems are overall one of the most dangerous behaviour tools used in schools and in society for neurodivergent children.

Reward systems are different to modalities such as everyone having a pizza party for getting through the year (at the end of term), **as long as everyone is invited, regardless of their academic performance and/or behaviour.** Celebrations such as these are not rewarding anything other than attendance and the person doesn't have to do anything in order to be able to celebrate with their peers.

I call indiscriminate pizza parties "celebrations". They aren't based on this reward system premise.

For further information about this, have a look at sponge bob, he says it better than me https://youtu.be/OGQx37dwnhM

For more info on aversive and dangerous behaviour reward systems:

https://docs.google.com/document/d/1JiBpVxSY0hha6BaUGRM6iRbO2lgU2LI3fmNARyNy8h4/mobilebasic

https://www.theatlantic.com/health/archive/2016/02/perils-of-sticker-charts/470160/

Changing our Lens about "Behaviour"

Understanding Presentations, or "Behaviour" Using an Informed Lens

Historically, the way children and adults' behaviour has been pathologised and desperate cries for help from vulnerable people have been ignored and viewed as 'attention seeking', 'aggression'& 'naughtiness'. Over the years, the voices of those who are Actually Autistic (AA) and ADHD (ADHD'er) have educated and informed us to change our lens and to stop seeing human need from a deficit based approach which ignores human rights and the human experience. The below table debunks some of the older, more archaic responses to people's presentations (or their "behaviour" as we once called it). The problem with the old way of looking at things ("lens") is it saw the on-the-surface 'signal' (presentation) and tried to stop the signal from being evident. In doing this, the reason for the signal to exist and the diverse factors which led to the signal being evident were often ignored. If we want to move forward and actually help people find ways to cope with environments which adversely affect their sensory being and with demands that de-stabilise them and make them feel threatened, we need to stop focusing on the way they communicate distress and start instead, focusing the factors which are causing them to experience distress in the first place.

OLD LENS	NEW & INFORMED LENS
That child just randomly threw a chair through the glass door. He didn't seem upset or anything. He was obviously bored and demonstrating attention seeking behaviour.	This child is likely to be experiencing sensory dysregulation, in conjunction with being ADHD. When he's dysregulated, he feels agitated and unsettled in his body and cannot settle his impulsive reactions to things. Further to this, ADHD affects the brain as a hyperfocus on exciting topics, thoughts or ideas and can be overwhelming in intensity. It's likely that this child was experiencing sensory dysregulation, unable to control his impulses and got hyperfocused on the noise, feeling and sensory input he would receive from throwing that chair towards the glass door.

OLD LENS	NEW & INFORMED LENS
	Respond by increasing the child's proprioceptive sensory input (more jumping, more impact play, more rolling, more banging and smashing things in a safe way, more swings, more tumbling).
That child throws a huge tantrum each time his mother shows his sister attention and every time he doesn't get his way with children. He needs to be taught social skills and needs a punishment from his mother. He's probably like this because his mother doesn't punish him or manage his behaviour properly.	This child is likely to be experiencing '**rejection sensitive dysphoria'** (RSD) and subsequently has high registration for interoceptive sensory input (interoception is your thoughts and feelings). This means that this child experiences his feelings at a really heightened level and they are often overwhelming to him. It's very likely that this child needs additional levels of affection and nurturing and additional levels of emotion in the responses from those around him to feel regulated and stabilised. If this child doesn't experience heightened feelings of comfort, security, love, and emotional bonds from people in close relationships with him, he is likely to experience overwhelming feelings of rejection and abandonment. Children and adults with RSD can spend their lives feeling unwanted and experience what others believe to be significantly severe states of depression and anxiety regarding interpersonal relationships. **Respond by** stabilising the access for the child to people who he has close relationships with. Increase the amount of time he has with these people (mum/dad/close relationships) and ensure he knows when he will see them. When he's with these people, make sure they know that it's important to show lots of affection and provide much more emotional validation to them. Being in their presence if you're working or doing something else won't feel like real presence as your attention is directed elsewhere. People with RSD need real, focused attention and

OLD LENS	NEW & INFORMED LENS
	are wary or baseless compliments or fleeting connections with people. If they don't feel wanted and needed, it can lead to an overwhelming spiral of intensified feelings of rejection.
That child is very rude and doesn't say hello, goodbye, nor shake people's hands when we meet new people. She sometimes will yell, scream, and pull away when I ask her to politely introduce herself. When meeting new people, she doesn't look at people and seems to totally ignore what they are saying. She will often want to keep playing on her device, or just have a tantrum whenever we go anywhere. She needs to be taught social skills and be taught to be polite and to communicate with other people in a more respectful manner.	As a world, we need to accept once and for all that the majority (neurotypical "NT" people) should not be allowed to dictate what is respectful. The majority (NT) should not be allowed to set a series of communication requirements and socialisation expectations and then expect and require all other neurotypes to conform to this. 1. Every child can communicate. Not always in a way that other people understand clearly. But that's not the child's issue. A lack of understanding is not the same as a lack of communication. 2. Every child knows and possesses their own way of playing and has their own social skills which meet their needs, and which help them have social input in a way that makes them feel safe, happy and gain enjoyment from being in the presence of others. Children possess this from birth **without intervention**. These skills don't always yield friendships easily and sometimes children change the way they play as a result. But they change and learn social skills themselves based on meeting their own needs and attaining the outcomes they want when they are around other people. One of the most arrogant and disrespectful things an adult can do is assume that they know how to socialise **better than** the child. 3. A lot of neurodivergent individuals do not like small talk, baseless irrelevant conversation, wasting time, or superficial socialisation. A lot of neurodivergent

OLD LENS	NEW & INFORMED LENS
	individuals are **very purpose driven** and see no point in saying hello to people who don't interest them, nor introducing themselves to people who don't seem to mean anything to them. A lot of neurodivergent people have brains which are easily focused on doing things, achieving things, experiencing things and not on superficial social encounters. Why should we all have to meet the same social nuances as our peers? Why do we have to waste 5 minutes every time we enter an environment, just to smile and suppress our desire to engage in the purpose of our visit? If something or someone doesn't seem or feel relevant to us, why aren't we allowed to keep playing on our iPad while our parents engage in the baseless socialisation that they love? Further to this, there is a heavy 'cost' (time/labour) of these interactions and this energy is better saved for navigating other situations and not unpurposeful interactions, such as these. 4. There are many **forced interactions** in society. They are 'forced' because children get in trouble when they don't do them. Schools have charts on their walls mandating them, parents demonstrate sadness and disappointment when their own children don't use them. These include saying hello, goodbye, making eye contact, smiling, keeping hands and body still, standing quietly, not making noises or stimming. Forced interactions make neurodivergent people suppress their bodily needs and functions and are very damaging to their wellness and overall mental health. Forced interactions are

OLD LENS	NEW & INFORMED LENS
	interactions which **are not important, nor required** in neurodivergent socialisation and should not be forced upon neurodivergent people just because these interactions make neurotypical people feel good about themselves.
The child purposely does things I've told him not to! I will go through rules with him and then he will break every rule. It honestly looks to me like he's doing it on purpose and wants the attention of getting in trouble from me. Sometimes I think he goes out of his way to ignore everything I ask of him. I've been told it is attention-seeking behaviour and I need to ignore it and set better rules and boundaries. I keep doing this, but he's starting to get pretty explosive and can be really violent at times.	A component of Autism is something called **pathological demand avoidance (PDA).** This isn't someone who wants to be oppositional, and this isn't someone who is just trying to always be the boss. PDA comes from a place of fear and trauma and is a pathological need for the person to feel protected and safe. When neurodivergent children are born into neurotypical (majority) worlds, they experience trauma from birth as a result of aversive sensory input (noises / smells / sensations which are overwhelming and actually painful to them) and they are told to ignore their bodies in order to meet social nuances and expectations. As a result of this, they often experience extensive pain and trauma from these demands placed upon them and the resultant sensory overload that they experience. This leads them to be extremely wary of these demands and develop a trauma-based response to demands. This trauma-based response to demands is **pathological demand avoidance (PDA).** PDA is not done by intention, it's done out of fear. It can feel dangerous to follow rules or stipulated expectations due to how painful they've been in the past. The person will literally be triggered by a demand as a result of this. PDA presents as someone who is actually self-motivated to not comply with demands due to the fear they pathologically experience when demands are placed upon them. If you give a child or adult a list of demands, you are effectively giving them a task list of things they must do and achieve to keep themselves safe.

OLD LENS	NEW & INFORMED LENS
	"Jimmy, when we get to the pool, don't run, don't push children and don't jump in the deep end. Remember? These are the pool rules." This simple comment or instruction translates as "*when you get there, run first, then push someone, then jump right in the deep end as soon as you can if you want to feel safe".* When the child does these things (breaks the rules), they then get in more trouble and the trust between the adult and the child continues to weaken. Respond by using language which is PDA friendly. This language is subsequently also friendly to the rest of the population and could be used easily with everyone. PDA friendly language includes using questions to establish expectations and reminding the person of the outcomes of their decisions and what the natural flow of life will be if they make certain choices. Examples below: Me - "*I love coming to the pool, it's so great here. I hope we can stay for ages."* Child – "*Me too, I can't wait to run in there and jump right into the pool!"* Me – "*Jump in? Ohhh…. Fair enough. So, we won't be staying long? Bummer, I was excited for a swim today.* Child – "*What do you mean? Yeah, we can stay all day!!"*

OLD LENS	NEW & INFORMED LENS
	Me – "*Nah… they kick you out once you run. Remember that kid we saw last time? But anyway, it's ok, you do what you want and I'll think about what our next activity is as we will get kicked out of the pool as soon as you run… Hmmmm… what else do you think we can do?"* Child – "*But I want to stay at the pool."* Me – "*Ok… well, that's up to you. Let's see how we go. How exciting!"* Confirming and displaying the natural outcomes of their decisions is the most helpful way of helping a child with a strong PDA profile to make decisions which are more likely to benefit them. Setting rules and boundaries is the quickest way to trigger PDA and make the child feel unsafe.
That child keeps saying rude words like "penis" and "vagina" and making comments about people's bodies. They are doing it quite repeatedly and in a grade 5 classroom it's totally unacceptable. Where has the child got this sexualised behaviour from and why are they being so disgusting?	Children with an ADHD brain are excited by scandal and love the shock response from others. Shocking someone or doing or saying something which makes someone display a strong response is an instant hit of dopamine to the brain. This is why there are so many adult ADHD'ers who love starting arguments online in blogs, on Facebook and love making controversial statements. It's often just to shock and startle other people and get that delicious pump of dopamine to the brain as a direct result of the attention and focus they suddenly get. As ADHD'er children, this same dopamine hit is needed, but the children don't quite yet understand why it feels so good to get this from adults or what the impressions to others can be due to their behaviour. Children can hear something that they repeat (such as a phrase from a song, or a word they heard on

OLD LENS	NEW & INFORMED LENS
	YouTube) and be saying it randomly, or scripting. Suddenly, someone stops them and provides this shock reaction and tells them: "*Don't say that as it's very rude, you should not say that at all."* Suddenly, the combination of PDA and the delicious smash of dopamine hits their brain and all they can think about is saying that again. If they get punished enough, they will probably try to not say it around that person but will be waiting for their next opportunity to say these words and see what the next delicious response might be. Respond by not acting shocked or surprised when scandalous things or inappropriate things are said. Respond instead by shrugging, appearing bored, saying "*whatever, that's boring, but <insert sudden exciting tone of voice> I'm super excited to do this and for you to show me how you drew that superhero again!!*". If you provide energy and excitement about a different thing, you are likely to help the person shift their hyperfocus and stop saying the scandalous phrase because they no longer get the delicious dopamine hit from doing so.

Reward Deficiency Syndrome

Reward Deficiency Syndrome (RDS) means the person will be primarily driven by seeking reward as this provides the essential dopamine hit that their brain exists in constant search of. People with RDS can appear unemotional due to how focused they are on their purpose, or goal. Some could say they appeared to have no empathy at times. However, there is no lack of empathy generally, but sometimes their focus and goal is more consuming than their capacity to notice the needs of others.

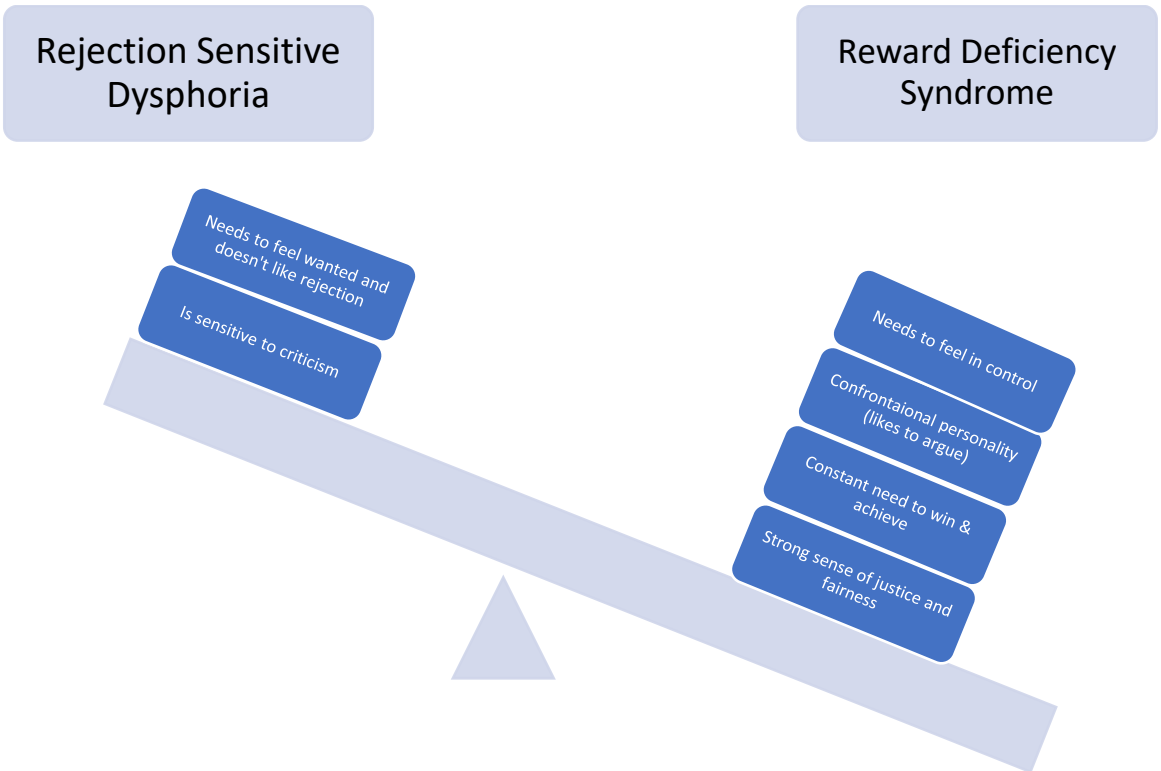
There is much less written about RDS, but it is essentially being driven by reward and focused on achievement. This is very related to ADHD and the hyperfocus and people with this presentation can often appear very unemotional and very motivated and driven. This presentation exists to an extent in everyone with ADHD (much like RSD), but to more and lesser extents in some people.

RDS can look like:

- A person focused heavily on winning and loving competition.
- Usually very intelligent in at least one domain.
- A person who prioritises winning as more important than connection.
- A person who loves incentives and rewards and hyperfocuses on pushing themselves with frequent, challenging tasks that they like to measure.
- A person who loves achieving everything on their list and creating new lists to achieve.
- A person who appears manipulative and controlling to others.
- Many natural leaders are likely to have a strong RDS profile.
- People who are Intellectual stimmers (this means they 'self-stimulate' through discussion, conversation, or other intellectual pursuits which nourish their mind).
- Very driven and focused on what they want, and mostly unwilling to compromise.
- Very difficult to control if they don't share the agenda of the person directing them.

- Fixated on their pursuits, very purpose driven.
- Can appear almost unemotional due to how focused they are on their purpose, or goal. Some could say they appeared to have no empathy at times. However, there is no lack of empathy generally, but sometimes their focus and goal is more consuming than their capacity to notice the needs of others.
- Very oppositional in nature. Strong PDA profile which is not just fear of being controlled by others, but also a fear in not being able to acquire the outcomes they need, without absolute control.

Many living with RDS will struggle to maintain friendships with others as a result of defiance. If people don't do things the way that they believe they should be done, it is likely to end in rejection, or more intense insistence. Many with RDS will verbally assert themselves and tell others what to do. When determining RDS, it's most helpful to assess it in contrast to the presentation of Rejection Sensitive Dysphoria (RSD).



Respected internet-based information repository on ADHD, ADDitude[10] produced an article on Reward Deficiency Syndrome which included the following explanation:

> *"Learning from experience is the basis for sound decision-making, and the motivation to learn is modulated by the promise of reward. The current Incentive Salience Model describes a dopamine reward system that is responsible for motivation, positive reinforcement, and pleasure for all brains. However, dopamine-increasing behaviours are even more gratifying to ADHD brains.*
>
> *Key aspects of the reward system are underactive in ADHD brains, making it difficult to derive reward from ordinary activities. These dopamine-deficient brains experience a surge of motivation after a high-stimulation behaviour triggers a release of dopamine. But in the aftermath of that surge and reward, they return to baseline levels with an immediate drop in motivation.*
>
> *One of the many consequences of reduced dopamine in the synapses is that the significance of tasks is decreased. If most stimuli appear equally compelling, it's difficult to attend to the most important task. As a result, stimuli need greater personal relevance — larger, more immediate, or repeated rewards — to be attractive to ADHD brains. Reward Deficiency Syndrome (RDS) has been proposed to explain why ADHD brains need stronger incentives. Deficits in the reward pathway, including decreased availability of dopamine receptors, decrease motivation. Indeed, ADHD brains struggle to sustain motivation when rewards are mild or are linked to long-term gratification. As a result, ADHD brains search for stimulation that can increase dopamine more quickly and intensely. Ultimately, the pursuit of pleasurable rewards may become a potent form of self-medication. In fact, dependent brains exhibit similar dysregulation of the dopamine reward system…*
>
> *For some ADHD brains, optimal functioning involves augmenting the existing stimulation — **seeking louder, faster, bigger, funnier, and riskier — the more intense, the better. Boredom is a common complaint for the owners of these brains. For them, it is physiologically uncomfortable when their under-aroused brains struggle to engage with their environment. In fact, in mundane, low-stimulation situations, these restless brains may compel their owners to increase the intensity level with fidgeting, noise, laughter, or conflict, if there is no other route to high stimulation available**. These more impulsive ADHD brains have their own logic: If some*

[10] https://www.additudemag.com/brain-stimulation-and-adhd-cravings-dependency-and-regulation/

stimulation is good, more is better. This is the signature short-sighted philosophy of brains compelled to choose immediate rewards over long-term gratification.

Other Presentations

RDS is not well researched yet, there will be much more information to come. But it's suggested that RDS is also likely to be the reason for many children or adults who present as follows:

- Obsessive, and repetitive behaviour, often regarding listening to the same section of song, or watching the same section of a movie/show.
- Fixated on certain interests and totally disengaged from anything outside of them.
- Those focused on the sensory world and appearing to only be motivated by meeting their sensory needs. This is the reward centre of the brain, nourished by achieving sensory balance and unable to be regulated without constant sensory bliss.
- Repetitive behaviours and fixations with items, people, sensations. Anything showing that the person's brain requires a regular input of preferred stimulation.
- In adults, this is very well linked to obesity (food obsession), alcohol and drug obsession and dangerous behaviour. Essentially people whose brains are driven by reward are more focused on the reward than on the impact of getting the reward (e.g., Hurting those around them, or danger to themselves). This behaviour can include high-risk behaviour.

How do we work with a person who has the predominant presentation of RDS?

- Try to remember that they are driven and focused, and don't always realise that their tunnel vision might be hurting or offending those around them.
- Help them to see a purpose and outcome in things, to help them remain engaged in them.

- Help them to find ways to be in control of not being in control. E.g., If they are struggling to make and maintain friends because they become too directive, then help them to set up a plan to keep friends by planning their own behaviour differently and reaping the rewards of the outcome of having friendships.
- Make things into challenges which require their brain to be engaged, in order to fix/solve them. This might be achieved by making normal rules and routines, into methods of experiencing reward.
- Increase the intellectual stimulation available to them. Play word games and have fun, harmless pranks, and trickery to keep them engaged.
- Find another person with an RDS brain to help you, if possible. The RDS brain is very clever, very focused on its topic of interest, and very driven.
- Find ways for the person to get the reward they need. Taking it away isn't an option. Find a way for them to access it, without significant functional deficit in other areas. This one is tricky – but we can't change the way their brain works. Help them see consequences of their actions.
- Challenges and tasks that you set are likely to just appear like demands to this brain. Unless the person sets their own challenges and tasks, they will be unmotivated (except perhaps when they are a child and still driven to show parents how much they can achieve). Covert challenging is ideal – set a challenge for yourself or someone else, in earshot of the person. Make it sound hard, yet enticing, and don't involve them at all. This is likely to spark some interest.

Oppositional Defiance Disorder (ODD)

Similar in presentation to Pathological Demand Avoidance (PDA) which exists as part of the Autistic presentation, ODD exists in those who aren't Autistic, but still exhibit similar characteristics regarding defiance and demand avoidance.

Oppositional defiance disorder (ODD) is a condition characterised by oppositional behaviour including deliberate and intense attempts to avoid complying with any demands and anger and frustration related to authority, or even just perceived authority from others. ODD can exist for a number of reasons, including:

- Undiagnosed Autism, in which case it's usually PDA that the person lives with but isn't diagnosed Autistic for some reason.
- Trauma-based disorders. Many people who've endured trauma, especially childhood trauma and abuse will have oppositional responses to anyone with real or perceived authority.
- High anxiety. People with high levels of anxiety can appear very demand avoidant and oppositional as a result of anxiety and their need to feel in control of their environment.

Simple strategies to work with someone with ODD include:

- Don't tell them what to do. It will never work and is bound to lead to arguments and escalations in behaviour.
- Provide them validation in the manner they need it and to the extent that they need it. If a person doesn't feel regulated (e.g. Their needs haven't been met), then they are likely to be more demand avoidant and very oppositional.
- Work on building relationships of trust first and foremost. Without trust and regulation, a person cannot have successful and positive friendships or relationships with people.
- Don't focus on 'wins'. This is people's lives, and they deserve respect and dignity of risk. It's never about whether you had a win and they did what you asked.

- If you are working with someone with a Trauma-Based Disorder, make sure you've been trained properly. See our other information sheet on Trauma-Based Disorders to ensure you understand the underpinning needs a person has.
- Always use PDA/ODD scripting. Never be directional. Always use questions.

Other Way's to Say NO & PDA/ODD 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 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 [insert person 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?"*

PDA/ODD Scripting includes finding ways to say things without making them a direction, yet instead, providing them a question which is loaded with natural consequences.

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.

Non-PDA/ODD way to approach this: *"You can't buy junk food or you'll be kicked out of your home. No junk food."*

PDA/ODD way to approach this: "*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?"*

Situation 2: 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 when they get home again.

Non-PDA/ODD way to approach this: *"Don't go into Jack's room. You're not allowed and you've been told this."*

PDA/ODD way to approach this: "*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."*

PDA/ODD 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/ODD scripting feels awkward to people as it's not directional and we are all so used to being directed by others. PDA/ODD 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/ODD is likely to test you by making some poor choices and seeing if you take back control.

Replenishing Drama and Excitement

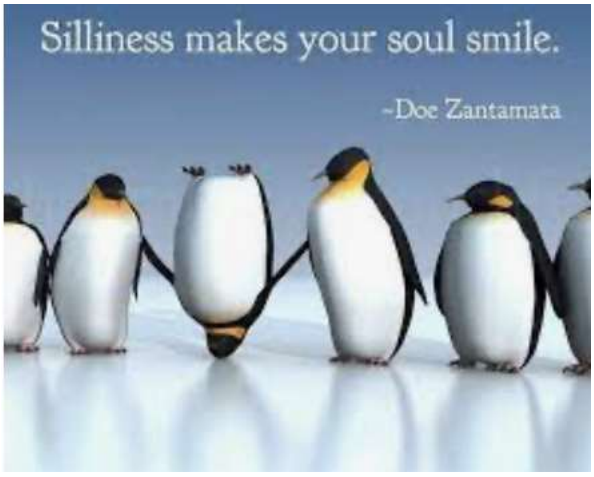
It's not unusual for some of the people we might support to start to become bored of the everyday lifestyles they lead, especially when they have well-trained support workers who reduce and sometimes eliminate harmful risk, drama, and negative stimulation. In many situations, reducing and eliminating stimulus such as this is positive for the person/people regarded, but in some situations, some individuals are adversely affected by the sudden lack of drama, excitement and energy in their lives and they start trying to source it themselves, using their own behaviour.

The purpose of this strategy is to:

'Find ways to provide dramatic energy and increase the excitement and silliness in people's lives who are lacking and missing it.'

Reasons that people might need drama and excitement artificially provided/supplemented include:

- The person might have had a family that included a lot of drama and dramatic situations and this was a very normal existence for them. For this reason, they don't feel safe and are not regulated without this excitement in their lives and they feel quite empty and bored without it.
- Some people crave excessive interoceptive sensory input. This means they love amplified feelings and want to experience things at heightened levels. This would lead the person to want and crave stronger expressions of emotions and more intensive demonstrations of need, want and craving.



- People who are bored. This might sound silly, but many of us need excitement in our lives and crave it. Just as some people don't like excitement and drama, others absolutely love it and need it.
- Some people struggle to communicate their needs and will understand and resonate with expression and tone, rather than words. An example of this might be that someone is very mad at someone and trying to express it, but their expressive communication is not at such a level that the person they are communicating with can understand exactly what they are saying. However, the communication partner is aware that they are mad. If the communication partner also expresses this same angry tone in sympathy and empathy of the person's frustration, then it makes the person experiencing this anger feel validated and heard.
- Some people we work with may have lived a substantial part of their lives in institution-style environments which were large, had many people, lots of noise and lots of drama. Regardless of whether this person liked the noise and drama or not, it's probably familiar to them and makes them feel safe. Often change can be very hard and very de-stabilising. Going from busy, loud, dramatic environments to quiet units with caring, stable workers can be a very difficult transition. In situations such as these, there have been observed issues with some residents, who don't feel settled in the quiet, and don't feel safe without the drama and busy environments around them.
- Further to the above point, some support environments thrive on consistency, stability, empathy, and nurturing. These are great foundations to help a person and necessary as platforms to learn, grow and develop. Sometimes, the one thing missing from some of these environments can be silliness and fun. Sometimes workers focus so hard on being stable and courteous, that they forget that some people also love to laugh, be challenged, do funny and silly things and giggle incessantly about things. The silliness and fun can be a significantly lacking ingredient in the support set up of many clients and the results can lead to depression, boredom, disengagement, and disinterest.

Providing drama and excitement to a person can fulfil the following needs:

- Increase the levels of excitement in the person's day-to-day life.
- Provide some energy to the person and make them feel exhilarated.
- Make them feel like they are back with their family / previous living situation that provided this to them in the past.
- Help them to feel well and regulated.

- Help the person feel like they have been listened to and acknowledged.
- Help the person to express themselves in such a way that makes them feel validated.

What if it feels weird to be silly?

For some people, being dramatic and silly is easy and a part of who we are. For others, it can feel forced, artificial and embarrassing. We will each use a strategy like this uniquely and based on the way we enjoy life and the way we like to be silly. Watch the person you're working with too – have a look and notice what they enjoy and what is fun and silly to them.

It's important to push yourself to see the importance of structured fun and silliness in the lives of those we support. Think about times at home when you are silly and when you laugh and find fun in odd or weird things that others may think are silly. Also, watch the result of others being silly and having fun and observe how much happier it makes the person you're working with. Naturally, it's only a strategy we would use with those who love it and who get enjoyment from it.

How do you replenish drama and excitement in someone's life?

The key to replenishing drama and excitement is in knowing the person's interests, exaggerating responses, laughing more, showing your feelings with gestures and more words and over-emphasising communication.

Some key tips are:

- Pick stories about movie stars doing scandalous things and use these as subjects to talk to the person you're supporting about.
- Have your own stories about silly things you've done (that you're happy to share) and have a laugh with the person about them.
- When things happen, increase the energy in your response. When you'd normally just say "*Oh no, that's not good*.", instead be more dramatic, include physical gestures and body movements and use your tone of voice to say "*Oh gosh…. Are you kidding? What on earth?? Why did that happen? That's terrible! Oh nooooo*."
- When you're happy, be really happy – do little happy dances, or sing little songs, or make funny hand movements to show you're happy.
- Add some silly phrases or funny sayings to things you do, this will remind you to do / say these funny things every time you complete this task – it could include washing your hands, or cooking food, or helping the person transfer.
- When creating situations of drama, don't use current workers or real people in the person's life. It's best to use movie stars / celebrities etc., or it's likely that the person will project things onto the actual person. E.g., "*I just read that Elton John had an affair – can you believe it?*"

What not to do when being silly

Naturally silliness can go too far and be unhelpful when not done with mutual enjoyment, reciprocation and respect. Making fun of people is not OK, using unprofessional language,

such as derogatory comments is not OK and making negative comments about other workers is not OK. Silliness should be designed to not hurt anyone and not marginalise people. Some tips to injecting fun, silliness and drama into someone's life in an appropriate way are:

- If you're going to mock someone, only mock yourself. It's the safest way of making sure you never offend anyone. People may invite you to mock them, but it's never a smart thing to do in a workplace. Use yourself as the object of being mocked, this way you can control it.
- Don't volunteer private information about your life that you're not open to being discussed. Have a good think about information that's appropriate to discuss and share and information which should be kept private and/or is sensitive.
- Don't make up lies or go along with lies unless they are ridiculous enough that they are not believable. Example below:

  Client: "Julie ate all the food."

  Worker: "Oh gosh, all of it? Did Julie eat the food in all these cupboards?? Holy Dooley, Julie must have been hungry this day."

  In this example, it's just silliness and unlikely that anyone would believe that Julie actually ate an entire kitchen worth of food.
- If you're unsure if your silliness is appropriate, ask your Team Leader / Coordinator or Specialist Behaviour Practitioner. There is often a fine line between appropriate and not appropriate and this line is often very person and scenario specific.

Screen Time, Devices & Gaming

"It's bad for children to spend too much time on devices, they need to be out, playing with friends and playing in the yard like I did when growing up."

"It's going to teach him/her really bad things if he/she is constantly on devices."

"It can't be good for their eyes to sit there for such long periods of time."

Although the above are common thoughts and feelings and heavily ingrained in society, they are not shared by the adult Autistic community. An Autistic person is quite different to a Neurotypical person for many reasons. This includes different interests, different needs, different sensory processing profiles and a different way of processing information. This is explained throughout this information sheet a little more with the aim of helping you understand that screen time for Autistic children and adults is a lot more positive than what the world seems to believe.

Autistic people generally don't crave social experiences – this is different from craving play with other children though.

Neurotypical (NT) children love the social and emotional warmth they get from engaging with other children. They love feeling wanted and love feeling loved by others. NT children will often talk about how close they 'feel' to others, and they need time with children to bond, develop emotional maturity and feel emotionally validated by the connections they form. The

Autistic person is more purpose-driven than this and craves people for 'playing with things', 'meeting a purposeful need', 'making playtime even more fun', 'creating noisy, fun environments' and 'sharing my special interests and teaching other people about things I love to talk about'. This is very different and although it's quite true that many Autistic children and adults still love to socialise, they generally don't do it for the same emotional reasons and thus don't 'need it' for their self-esteem, it's just another toy which is fun at times to play with.

Autistic children and adults' sensory profile usually requires much greater extremes in seeking input and avoiding input than neurotypical children and adults.

Many Autistic children and adults live with very complex sensory profiles which require extensive amounts of some sensory input and dramatically hate and avoid other types of sensory input. Just like a person who loves listening to a certain song on repeat, or needs excessive movement to feel settled, a person's sensory profile is so important and not a choice or a want, but instead, it's a NEED. A person cannot pretend their sensory needs don't exist, so it's important to help them meet them. If a person's sensory needs are not met, they will feel dysregulated. Feeling dysregulated means you don't feel OK and don't feel settled or right. People who are dysregulated are often erratic, with poor impulse control and might have ineffective or no verbal communication.

Learning skills and being stimulated in social situations is awkward, hard, and sometimes torturous for Autistic people.

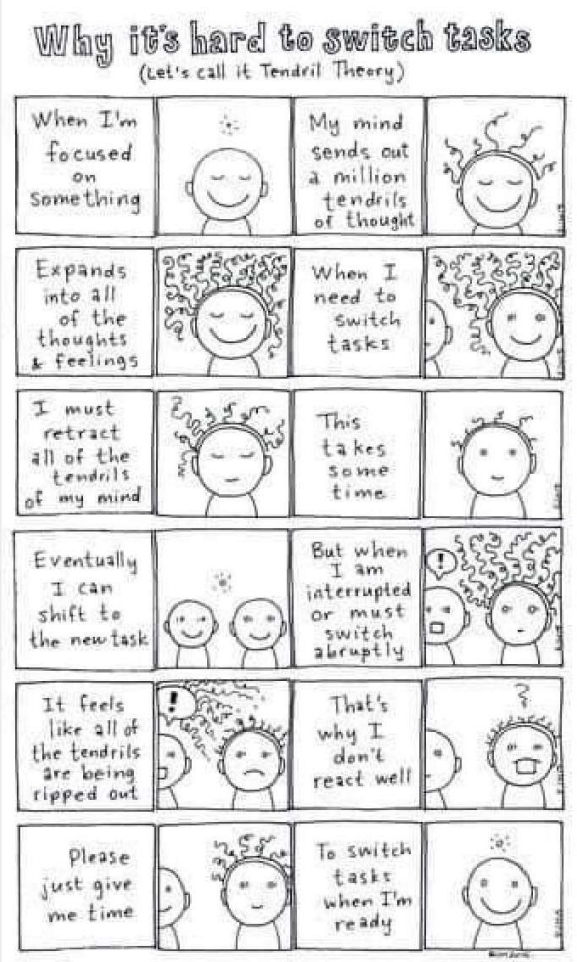
Being on devices enables people to learn, to be entertained, to be excited, to be stimulated and to engage with others online, thus having friendships, learning to work as a team and learning how to make friends and feel valued as a team player and member. These experiences often are not available for Autistic people outside of an online environment due to the significant impact that social pressures and expectations limit their interest in engaging. Social trauma is also very common, and this can limit a person wanting to be around people at all. The online environment can enable learning of skills, interacting with other people, building friendships, and developing technical skills without the trauma of face-to-face contact or all other expectations and pressures already mentioned.

Feeling valued, clever, gaining a sense of achievement and being liked is a core and fundamental need for all people. Yet, if you aren't allowed to do gaming and you're Autistic, where do you get these needs met?

Being online and gaming provides an awesome opportunity for children and adults to have big wins, to develop their confidence and to be respected by their peers. In some situations, this is the only opportunity they have to meet their needs of feeling valued, wanted and needed by others in a way that means something to them. For quite a lot of Autistic children and adults, this need isn't met in any other way. They are often told they aren't being compliant, school is often a place of trauma, due to how often they get in trouble and cannot meet their sensory needs and even family events can be awful and traumatic due to the social expectations and pressures that exist.

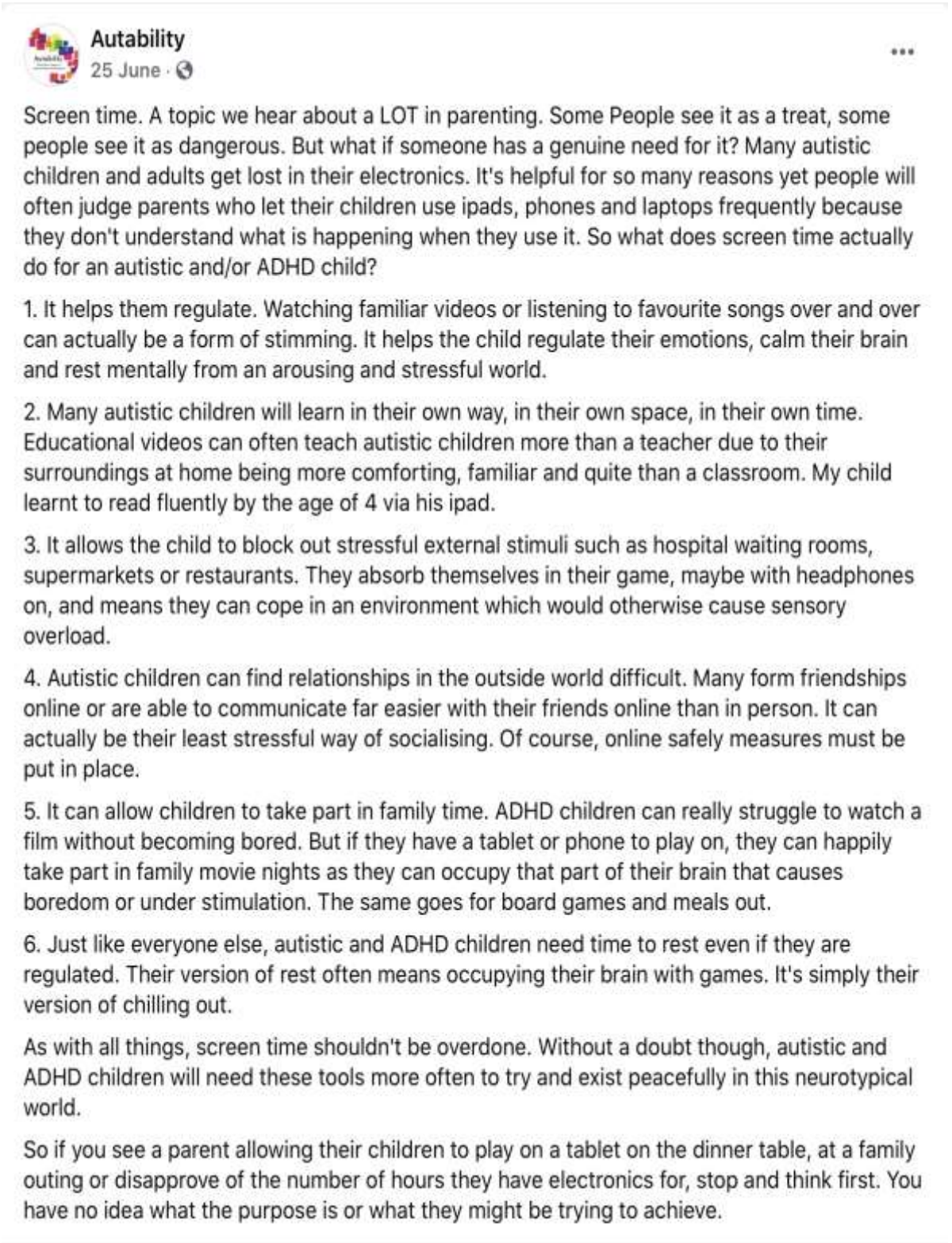
Transitions to doing something else is really hard and can be exhausting

One of the things that make some parents think that technology is bad is that changing to do something else is sometimes a very traumatic and exhausting experience. However, this is part of the nature of Autism and the way the brain can hyperfocus on certain tasks. It can be really hard to switch to something else and can feel like the person is experiencing significant loss and feeling very unsettled when this happens.



The Unsolved Problems and Strategies Information Sheet on Pathological Demand Avoidance provides a lot more information about how to help with transition planning.

The following was a Facebook Post by a group called Autability and speaks to some of the important reasons to not question parents who provide unlimited access to devices and don't impose restrictions.



Autability
25 June ·

Screen time. A topic we hear about a LOT in parenting. Some People see it as a treat, some people see it as dangerous. But what if someone has a genuine need for it? Many autistic children and adults get lost in their electronics. It's helpful for so many reasons yet people will often judge parents who let their children use ipads, phones and laptops frequently because they don't understand what is happening when they use it. So what does screen time actually do for an autistic and/or ADHD child?

1. It helps them regulate. Watching familiar videos or listening to favourite songs over and over can actually be a form of stimming. It helps the child regulate their emotions, calm their brain and rest mentally from an arousing and stressful world.

2. Many autistic children will learn in their own way, in their own space, in their own time. Educational videos can often teach autistic children more than a teacher due to their surroundings at home being more comforting, familiar and quite than a classroom. My child learnt to read fluently by the age of 4 via his ipad.

3. It allows the child to block out stressful external stimuli such as hospital waiting rooms, supermarkets or restaurants. They absorb themselves in their game, maybe with headphones on, and means they can cope in an environment which would otherwise cause sensory overload.

4. Autistic children can find relationships in the outside world difficult. Many form friendships online or are able to communicate far easier with their friends online than in person. It can actually be their least stressful way of socialising. Of course, online safely measures must be put in place.

5. It can allow children to take part in family time. ADHD children can really struggle to watch a film without becoming bored. But if they have a tablet or phone to play on, they can happily take part in family movie nights as they can occupy that part of their brain that causes boredom or under stimulation. The same goes for board games and meals out.

6. Just like everyone else, autistic and ADHD children need time to rest even if they are regulated. Their version of rest often means occupying their brain with games. It's simply their version of chilling out.

As with all things, screen time shouldn't be overdone. Without a doubt though, autistic and ADHD children will need these tools more often to try and exist peacefully in this neurotypical world.

So if you see a parent allowing their children to play on a tablet on the dinner table, at a family outing or disapprove of the number of hours they have electronics for, stop and think first. You have no idea what the purpose is or what they might be trying to achieve.

Why gaming is actually GOOD for Autistic children

from “Spectrum Gaming” (on You Tube)

This is based on the concept of ‘neural harmony’ which is a term designed to support people to find a common ground in understanding that we aren’t all alike and this doesn’t mean some are right or wrong. Neural harmony is about finding a safe space to be different. https://www.youtube.com/watch?v=IMV8XP7veaw&t=1s (full clip here, my points below have been taken from Spectrum Gaming and the you tube clip referenced).

1. **Learning Social Skills:** Not everyone has the confidence to socialise. Many have had negative and difficult experiences with other children. They have also found certain environments to be a sensory overload and thus not wanted to socialise due to lights, noise, people, smells etc and they avoid social environments as a result of this. However, being online and gaming with other people is a great way to avoid many of these issues and still have a social world with other people who are all aligned to your interests. Gaming is a great place to be able to learn social skills without having to be face to face.
2. **Learning Key Life Skills:** Some games are very complex. Some are required you to pick characters using strategical thinking and requires team-based play. Communication

and teamwork is necessary in order to work together successfully. Some games may look like "just a shooting game" but the games in fact are about dynamic problem-solving, critical thinking, communication etc. Games like Minecraft are known to people as 'killing zombies and building blocks', but this game takes strategical planning, and some have to map out castles, work out resources, work in a team collaboratively and using appropriate time management skills and leadership skills. You get to learn great life skills in an environment which is safe and doesn't have those social pressures or expectations that can be quite crippling for Autistic people. Lessons aren't often learned in those environments as the social pressures are too overwhelming to actually benefit from the life lessons buried underneath. Confidence is also developed as a result of developing skills in these games and occupying prominent positions in some of these games. Learning life skills is optimised when you can learn these in an environment that makes you feel safe.

3. Having a community: "Ready Player 1" is a great example of this. There is a quote in that which is *"being human totally sucks most of the time, video games are the only thing that makes life bearable".* In the real world you can sometimes feel so disabled and so terrible as a person who hasn't achieved what others have and haven't done the things that others can do and don't have a job the same as others do and generally feel like they've let down everyone due to their lifestyle choices. In games however, you can be the leader of a clan and have people who rely on you, who look up to you, who celebrate you and tell you that you're awesome and make you feel like you really know what you're doing and can achieve such amazing things. You can have so many positive experiences. In some situations, this is the only thing that makes you feel like you're succeeding. Another awesome quote from this movie is *"this is the oasis; we exist as nothing but raw personality in here".* This speaks to the specific communities which share your special interests, and you can find entire communities which also love trains, or Pokémon or whatever your interest is. Third quote (in response to the comment about the oasis, in previous quote) *"I beg to differ, everything about our online personas is filtered through our Avatars which allows us to control how we look and sound to others. The oasis lets you be whoever you want to be and that is why everyone is addicted to it".* Some people don't have meaning and acceptance in normal life. They don't feel they are meeting anyone's

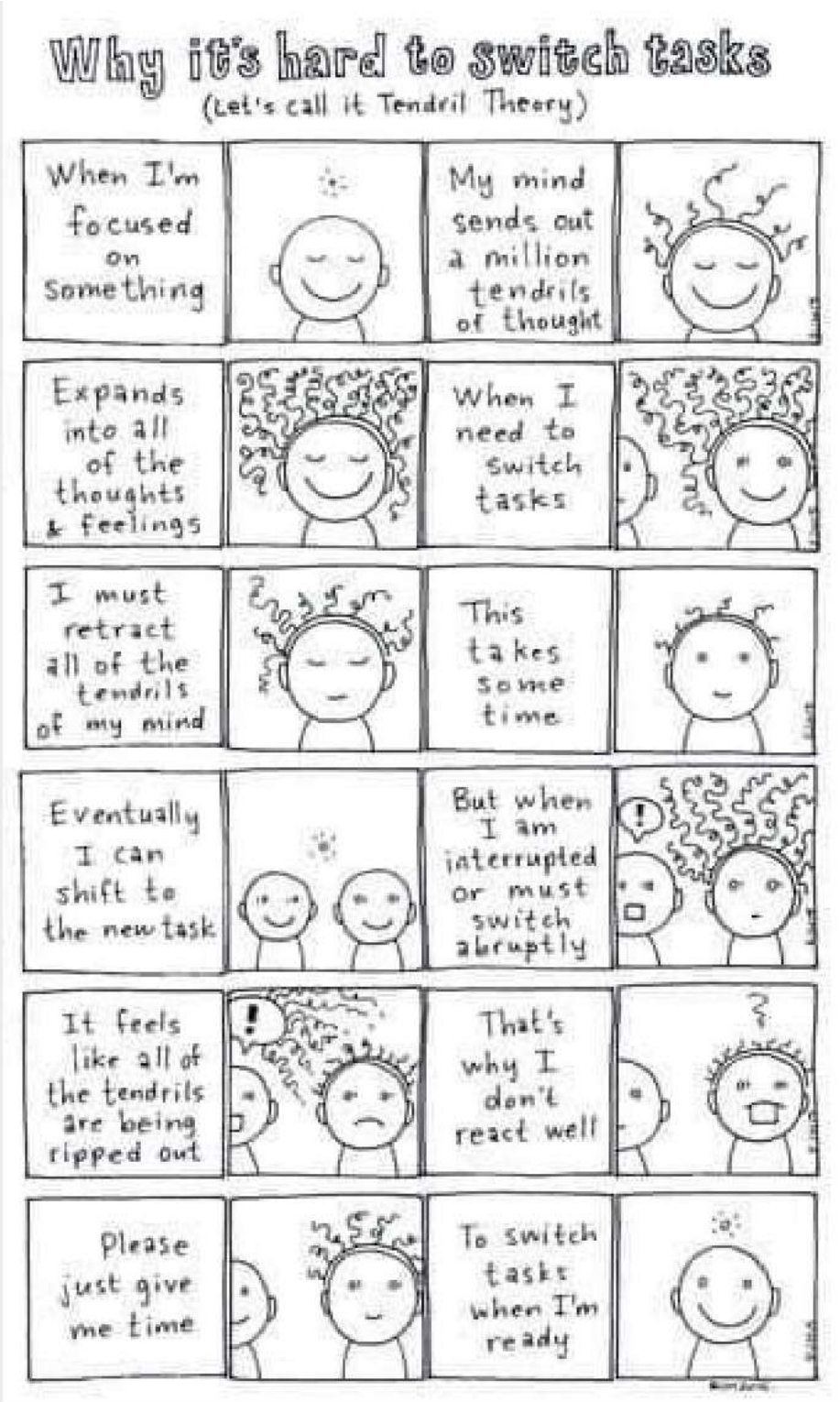
needs and really need and rely upon their online persona to feel validated and important.

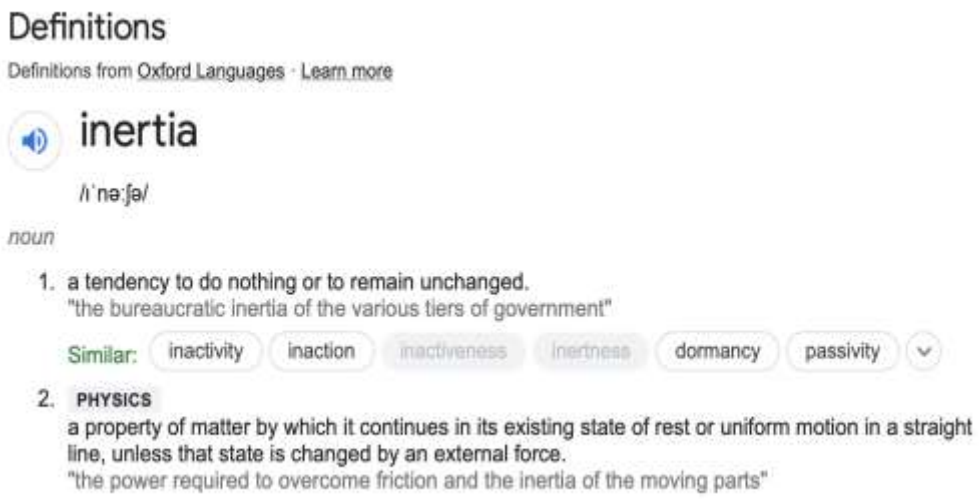
4. Sense of Achievement: Not all games are easy, some take hundreds of hours to get anywhere or achieve anything. When you have a great win on a game, you get the most amazing feeling and rush. Spectrum Gaming explains some of the huge challenges he has overcome in gaming and how complex it can be for some people. Achieving success in some of these games has provided immense validation and support to feel so able and successful. Gaming enables that immense sense of achievement and provides gamers the opportunity to not only develop skills, but to benefit from the amazing feeling of doing things that you know others cannot. Happiness is not a stationary thing – you can't get to one place and then suddenly always be happy. If someone wins the lottery, they will be happy for a while, then get back to how they were. Happiness is about making progress, goals and achievement. Gamers should be proud of their achievements.
5. Developing Friendships: Some really great friendships are made through gaming. The author explains he made his first friend online and although he's still never met him, he's been great friends for years. Making a friend online enabled him to go into the real world and not be afraid of making friends in the real world. Being able to make online friendships is really important as they can be a first step of stepping out into the real world and making friends in real life as well.

Hobbies are important to people; gaming should be no different to this and needs to be respected as a very important hobby to those who love to do it.

Autistic Inertia

Let's start by looking at "Tendrils Theory" below:





Autistic inertia relates to the inability to start something, then the inability to stop or transition from something started. Getting started can be hard. Stopping or changing can be hard. This is often explained with the Tendrils theory (in the picture on the first page).

The Autistic brain is monotropic. Monotropism is a term which relates to our polarised thinking and intense hyperfocus on things. This means that, unlike neurotypical people who can focus on many things at the same time with moderate levels of brain focus, we will focus intensively on polarised thoughts with a lot more intensity. This makes it harder for us to then shift these thoughts to something else.

In an article published in 2018 by Oswin the parallels to perceived laziness or intentional resistance is highlighted.

> *"So what does autistic inertia look like? It can look like laziness or resistance to change. When an autistic person has stopped for the day, or taken a break, or taken a vacation, it can be difficult to restart. This may look like resistance to getting out of bed in the morning, not necessarily because the person is tired, but because the steps to doing so are overwhelming. For school-aged children, this may be ending a school day and coming home and resisting to do homework, not out of laziness or out of an inability to do the work, but because they've kept it together for the day. They don't have anything else to give towards starting, planning and executing the homework.*

But that's just half the story. When you get started, for instance with something of interest, it can be hard to stop. Even if you walk away from the book you're reading or the video you're watching, it's still consumes your thoughts, your conversation, and your movement. It can be a repetitive motion, that once you start you may not be able to stop. None of this is particularly a problem until you need to meet others demands."[11]

Strategies

One of the tricks to responding to inertia **is to not highlight it.** Announcing change is hard for many people. Some manage this with timers and reminders and are happy with such accommodations. Others find reminders add to the feelings of overwhelm.

One of the best accommodations for someone experiencing issues related to inertia is a co-regulator – e.g., Someone who can help them move their brain to the next thing without them focusing on the state of transition. A simple example of this is to start talking about the next thing that they are going to be doing (the thing that will be hard to move towards). This might be demonstrated by the way our Therapy Assistants help children in our TecAntz Programs to be ready for going home. At approximately 20 minutes before home time, they start conversations such as asking "*what shows are you watching tonight at home?" "Ohh.. is mum making those meatballs you were telling me about tonight?", "what game will you play on your computer tonight – is it the one with the balls you were telling me about"?*

Essentially, we try to get the child's brain thinking about the next thing. This means that there is no transition for their brain, as it's already in the next place. This strategy is **very effective.**

Purpose Driven Brains

The Autistic brain is purpose driven and sensory driven. This means that we aren't motivated by doing things because someone wants us to, because someone thinks we should, or because it's the normal next thing to do. We certainly often aren't motivated because doing

[11] Oswin, 2018 https://www.divergentminds.org/a-look-at-autistic-inertia/ A Look at Inertia

something will make someone else happy (except for those with strong rejection sensitive dysphoria profiles – but that's a whole different information sheet). We require purpose in tasks around us, or we don't see the point. Going to school because 'we should' is unlikely to be a motivating factor, especially if some parts of school are not liked. However, going to school because "we need to go water the plants outside the classroom or they will die", or going to school because "we need to tell Mrs Smith about the awesome weekend we had on Minecraft" might be motivating enough to help our brains see purpose.

Transition Management (Autistic Inertia)

One of the hardest parts of Autistic Inertia is 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. 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 Pathological Demand Avoidance and Autistic Demand Avoidance 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.

Managing Transition - Transition is best managed by:

Preparation: Make sure the person is ready for and wants the transition to happen. They are likely to not feel this way at the time of transition, but preparation might include earlier agreements and/or discussions. Preparation may also include the use of timers with a countdown function and an alarm that goes off at the time of transition. Other options are lights, like the Nano Leaf ™ lights which can be controlled to turn different colours to prepare someone for a transition. Preparing for transition doesn't mean 'announcing' or 'highlighting' transition. It means that you have done as much as you can as a co-regulator, to make sure

the environment is best for the transition to happen smoothly, without excessive highlighting.

Cognitive Placement: Prior to the time of transition, some people are better supported by chats and conversations about the next task/situation that they are going into.

Example: It's time to leave McDonalds and go home to watch a movie. As the person is finishing their food at McDonalds, start a conversation about the movie you might be watching. Get a bit excited about the movie and maybe discuss where you're going to sit to watch the movie and anything else which 'paints the picture' about the movie watching experience. Just having a discussion like this can help put this into the person's head.

Distraction: At the time of transition, distraction can be very helpful to those who are not coping with change and are not wanting to transition to do something different. Distraction might include starting a conversation about something the person likes to do, in order to take their mind off having to change from one task to another. Distraction might also be doing something silly as the transition is happening, so they are laughing at, and with you, rather than focusing on how difficult the change / transition is. If the person is ADHD, then distraction is almost essential as so much of the person's brain is likely to be fixated on what they were focused on prior to the transition. If the person is ADHD, most distractions will need to be dynamic and excitable and repetitious in order to work.

Situations like below, are far too common and can be quite traumatic for the person. Note: The below is an example of what an unsuccessful transition can look like.

Father - *"It's time to go to Aunty Jenny's house."*
Son – *"No, I don't want to go to Aunty Jenny's house, stop saying that dad, stop it."*
Father – *"Come on, time to go."*
Son – (yelling louder, becoming tense) *"No, stop saying this, stay home, stay here, not going to Aunty Jenny's house."*

The child is then likely to continue escalating, crying, hitting, screaming that he doesn't want to do / go to the different thing.

Sample Transition Scripting (child)

[Preparation]: Father puts a timer on his phone for 30 minutes. At 20 minutes, father starts this conversation.

Father – *"I love how at Aunty Jenny's house we can have a cup of warm tea while we watch the football."*

Son – *"Yes, I love warm tea, can I have some now daddy?"*

Father – *"No, not right now, but I also enjoy how Aunty Jenny gets the big blanket with the blue wool, and we watch cartoons before the football starts, I love her pussy cat too and how he sits on her lap."*

Son – "*I want the big blanket this time and I want to watch Bugs Bunny now."*

Father – "*You can have the big blanket, once the timer goes off, we can go and get you that blue blanket."*

*Alarm goes off, signalling time to leave.

[Distraction]: Father drops a pillow on the ground, yelling 'touchdownnnnnnnn' "*I scored a touchdown, I bet you can't beat me, turn that off and meet me at the door."*

Son – "*I can beat you, I'm much faster, I'm coming now, don't forget the big blanket."*

So, rather than **telling** a person you are going somewhere (e.g., To the shops, to someone's house), it's better to not focus on the 'doing' and focus on what it will look like when you're there. Try to paint the picture, using words. Taking away the directional tone of your conversation makes it easier to manage.

In 2020 Quincy published a great article on Inertia which provided the following information.

> *"So if that's inertia, then what is "autistic inertia?" Well, autistic inertia is the tendency that autistic people have to want to remain in a constant state. When we're asleep we want to stay asleep, when awake we want to stay awake, when we're working on one thing we want to keep working on it, when we're doing one thing we want to keep doing that one thing, etc. Now, yes, this tendency exists in everybody but you must understand that this is often significantly more pronounced in autistic people. This can*

also (at least in part) be due to executive functioning struggles. (There are many other reasons why autistic people may have trouble switching tasks, but here we'll only focus on executive functioning).

Accommodations

So, now that we've gone over a potential reason why many autistic people may have trouble switching tasks, let's go over some things that I have found helpful or I have heard other people have found helpful when it comes to task switching/initiation.

The first important thing to remember is that executive functioning struggles absolutely do not represent laziness. I know that if you yourself don't experience executive functioning difficulties you might think this is all quite strange, because it "should be easy" because all you have to do is just "do the thing." However, difficulties with task initiation actually are a product of a very real cognitive "block" and very often can get in the way of our actual intentions."[12]

A few key, final takeaways from this are:

- Autistic brains are monotropic. This means they focus on singular, or polarized thoughts and frequently hyperfocus, rendering their attention spans limited to only this content.
- Inertia essentially means that it's hard to start something and hard to stop something, purely because there is too much of our brain to move across and it's just hard to do this (tendril theory).
- Help us by not focusing on transition. Instead, start discussions on the next thing that we need to do and help us put this in our minds. Don't discuss it as a 'transition' (e.g., Don't say "remember next we need to do XYZ", instead, just say "wasn't it funny when we found those Pokémon at the shops last week? Do you remember how many of them that shop had?" – This will put 'the shops' into the person's head and provides them a purpose to enable it to be easy to then go there.
- Inertia will be impacted by environments and purpose. If the person has no purpose to something, it will be much harder for them to switch to it. Focus on helping them find purpose in the next thing and it will become easier.

[12] Quincy, 2020 https://speakingofautismcom.wordpress.com/2020/03/24/task-initiation-executive-functioning-and-autistic-inertia/

Further Resources Which Might Help

Link	Description	Author
Fighting Autistic Inertia	Explanation of Autistic Inertia and how the author keeps her inertia and depression at bay.	Becca Hector, GeekClubBooks
First Hand Accounts of Autistic Inertia	An autistic led study on inertia, involving first-hand accounts of inertia.	Karen Leneh Buckle, Kath Leadbitter, Ellen Poliakoff and Emma Gowen.
Speaking of Autism - Inertia	Task Initiation, Executive Functioning, and Autistic Inertia.	Published by Quincy
A Look at Inertia	Information about Inertia	Oswin

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