## Notes to accompany the PowerPoint Slides for the E-learning module for parent-carers:

#### All Behaviour is Communication



Before you start:

- Please note that the PowerPoint which accompanies these notes has been divided into Part 1, Part
- Remember once a particular part of the All Behaviour is Communication PPT is open, to then open it up it in Slide Show View.
- You will need to have a copy of these notes open (preferably a hard copy version), in order to navigate your way through the slides.
- You may also want to consider doing parts of this training with your partner and/or a friend.
- You are welcome to pop an e-mail to sarahs karma@yahoo.co.uk at any stage should you need clarity on anything or have a specific question you would like to ask.

#### PART 1

#### Slide 1: All Behaviour is communication

This quote: 'English is my second language. Autism is my first.' was made by Dani Bowman. She is a young 25 year old, Autistic woman.



You can read about Dani Bowman and the work she does by clicking on the website below: https://danibowman.com/

#### Slide 2: Are Your Eyes Listening?

Sarah Stup's writings take readers inside the world of autism, so they may experience its very sights, sounds and feel.

'Writing is my way out of a lonely place where only God knows," she says. "I feel alive to type. The lid opens and out comes pieces of Sarah, a girl with wings who soars above the place with no hope called Autism. I am real when I write. Autism is my prison, but typing is the air of freedom and peace.'



Click on the link below and scroll down to watch excerpts from Sarah Stup's book, 'Are your ears listening?'

http://sarahstup.com/shop/are-your-eyes-listening/



## Reflection:

Read the excerpt shared on this slide:

- How does it make you feel?
- In light of the topic of this module, All Behaviour is Communication, consider how you could better ensure that your 'eyes are listening' i.e.
  - What could you do more of?
  - What do you need to do less of?
  - What do you need to stop doing altogether?

#### Slide 3: Module outline

This is an outline of the content that will be covered over the course of Part 1 of this module:

The Iceberg Analogy: All Behaviour is Communication

- The Social Discipline Window: Maintaining Social Norms & Behaviour Boundaries
- Become a Stress Detective: Reframe Distressed Behaviour
- Make Sense of Behaviour: A Functional Behaviour Analysis
- Reframe Behaviour: Can't instead of won't
- Behaviour through a Neurodiverse Lens: Autism from the inside-out

#### Slide 4: For today we forecast

Without thinking too hard, jot down, what weather forecast you feel would accurately describe how you are feeling right now?

#### Slide 5: Take home message



## Reflection:

- What do you understand by the phrase; 'All behaviour is communication'?
- Reflect on a situation you have recently experienced, during which time you experienced a particular behaviour of your Autistic adult child, as problematic.
- How do you think the above behaviour provided a solution for your Autistic adult child?
- If the case, in what way did you contribute to escalating your Autistic adult child's distressed behaviour in that particular situation?
- What could you considered doing differently in a similar situation in the future

#### Slide 6: Difficulty to communicate adequately



## Reflection:

- Think of an example of when your Autistic adult child experienced difficulty communicating how he/she felt and/or wanted/needed?
- How were you able to 'read' the subscript of your child's behaviour and determine what he/she was feeling and/or what he/she needed?

#### Slide 7: Distressed behaviour



#### Reflection:

- How would you describe your Autistic adult child's behaviour when you know he/she is clearly very distressed?
- What impact does this behaviour have on you?
- How do you generally respond to such distress?

#### Slide 8: Interpretations of observable behaviour: The tip of the iceberg



## Reflection:

- Which of the behaviours listed in the table on this slide have you observed in your Autistic adult
- How have your interpretations to what you have observed compared with those listed in the table?

#### Slides 9 and 10: The Social Discipline Window



Read the information below from the work of Lindsey Pointer on 'Learning to work with The

#### Social Discipline Window'

The Social Discipline Window describes four basic approaches to addressing behaviour that needs to be changed. Restorative practitioners use this tool to gauge the best response to a specific incident or ongoing issue. The four strategies are represented as different combinations of high or low control and **high or low support**. The word "control" never seems like quite the right fit to me, so I instead use "expectations of behaviour" or "accountability." The restorative domain combines high expectations of behaviour and high support and is characterized by **doing things** with people, rather than to them or for them. A restorative approach allows us to address the problematic behaviour, while also practicing empathy and maintaining a strong relationship.

Take, for example, a student who is repeatedly disruptive in class, speaking over the teacher and making loud comments and jokes,

The **Neglectful** strategy is to not do anything, to hope that the student will just eventually stop.

The **Punitive** strategy is punishment, doing something to the person who is misbehaving. The teacher might give the student detention or remove privileges like being able to come on a field trip. The strategy holds the student to a high expectation of behaviour, but has very little support. This strategy may result in animosity between the teacher and student, and will not address the core issues or needs contributing to the problematic behaviour.

The **Permissive** strategy is when we do things for someone. We accept their excuses or make excuses for them. The teacher might tell herself that the student is just trying to be liked by the other students because he has been having trouble making friends, or that his unrestrained enthusiasm is a sign that he is enjoying the class. A possible outcome is that other students, seeing that a high expectation of behaviour is not upheld, will similarly begin to speak out of turn, and the teacher will slowly lose the respect of the class and the ability to facilitate an effective learning space.

The **Restorative** strategy is when we work with the person to resolve the issue. The teacher would speak with the disruptive student one-on-one, explain the impacts of his disruptive behaviour, and respectfully ask the student about his experience and what is going on. This keeps communication open and allows the teacher to find out what needs are contributing to the student's misbehaviour.

Is the student having trouble making friends? Are there troubles at home that are impacting the student's behaviour at school? Are there other more productive ways that the student would like to be an outgoing leader in the classroom? Does the student need additional material to challenge him and keep him on task? The teacher and student would work together to understand what are the **barriers to meeting the behaviour expectations** and how can those barriers be addressed.

What strikes me about the restorative strategy for addressing behaviour issues is the **humility** it requires on the part of the teacher, facilitator, parent or other person of authority. Rather than thinking that we know best and approaching the problem with an already formed answer (as is the case in both the punitive and the permissive strategies), the restorative strategy approaches the issue by asking questions, with a humble and compassionate desire to better understand. It is the only strategy that allows us to actually get to the core of the issue.

There are a few strategies you can use to address conflicts and issues in your own life restoratively.

- Ask questions! Don't assume that you know why a person is doing something, what their needs are, or the best strategy for making things right. Remember to make questions open-ended (so they can't be answered with a simple "yes" or "no") and to use a tone of respect and non-judgment.
- In approaching an issue, follow the framework of the three central restorative questions.
  - O What happened?
  - O Who was affected and how?
  - O What is needed to repair the harms and make things right?
- Commit some time to **self-reflection** and identify which strategy in the Social Discipline Window is your default response. Are you prone to avoiding conflict and doing nothing, to jumping straight to punishment, or to making or accepting excuses for poor behaviour? Knowing this about yourself will help you to know which direction you need to push yourself. Do you need to remind yourself to hold high expectations of behaviour with the people in your life or do you need to remember to take a step back and show support?

In each of the communities and interactions that make up our lives, the Social Discipline Window offers us a tool for thinking about how to approach issues and conflicts more restoratively.



#### **Reflection:**

- Referring to slide 10; which window do you feel best describes your parenting/ your role as a carer?
- Think about a situation with your Autistic adult child, in which you are aware you moved from one window to another; what do you think contributed to this?
- When you feel you that you yourself, have not behaved very well, out of which window would you want others to respond to you?

#### Slide 11: Making sense of behaviour



Read the scenario below. Monica and Gabriel are married couple. The scenario describes an experience Monica encounters on her way home; Gabriel's mood after a tough day at work and their interaction on Monica's arrival home.

**Monica**: On your way home from work you were stopped at a road block. To your horror you discovered you'd left your driver's license in your other handbag which is at home. The traffic officer issues you with a £100 fine.

You are very upset and know that your husband will be furious. It was only the other day when he had said something like this would happen if you kept swopping handbags.

You arrive home determined to ensure that your husband does not find out. You are struggling to stay calm and are on the verge of tears. It is obvious from your tone of voice and your body language that you are upset, but when your husband asks how you are when you arrive home you answer saying you are **fine**.

You husband soon becomes annoyed. Before you know it he accuses you of always being miserable and says how tired he is of trying to make you happy. You feel yourself becoming angry and you accuse him of being self-centered and selfish. Before you know it you are arguing and shouting at one another!

**Gabriel**: You have had a hard day at work and are looking forward to a relaxing evening. You arrive home before you wife. A short while later you hear her car pull up and stop in the drive way.

You greet her and ask how she is. She answers 'fine' and something about the way she says 'fine' just presses your buttons and you find yourself snapping at her.

'You are always so miserable. It doesn't matter what I do, I just can't seem to make you happy!' She snaps back, accusing you of being self-centered and selfish. Now you are angry! You have had a tough day at work and this is the last thing you feel like; a moody, miserable wife. All you wanted was to be able to relax.

Before you know it you begin arguing and shouting at one another.



- What do you think Gabriel heard Monica say?
- Based on what you read; what do you think Monica actually needed, but was not able to articulate?
- How would you advise the couple to restore their relationship harmony?
- How could Monica handle similar situations differently in the future?

#### Slide 12: Behaviour is Communication

Look carefully at this graphic which uses the analogy of an iceberg to help us think about all behaviour as

some form of communication. Consider the idea of an iceberg. From the surface, bobbing up and down above the water, you can see an intimidating structure with its unstable crevices and potentially dangerous jagged edges. What you do not see is the enormity of it beneath the surface of the water and this is essentially what keeps the tip of the iceberg afloat.

Understanding behaviour can be done by making use of this particular visualization. If we look past the behaviour we can see (the tip of the iceberg) and travel beneath the surface (in the submarine) and redirect our focus to exploring the message our Autistic adult child is needing us to hear, but in that moment is not able to clearly articulate.

The analogy presented on this slide helps you to consider how behaviour i.e. the ability an individual has to manage his/her behaviour (self-regulation) is impacted by various elements of the 5 interrelated domains as illustrated in the table below.

Biological domain	Emotional domain	Cognitive domain	Social Domain	Prosocial domain
<ul> <li>Physical health, which includes a robust immune system</li> <li>Sufficient energy on waking up and maintained through the day</li> <li>Ability to recoup after difficult experiences</li> <li>Ability to remain calm amid distracting visual auditory stimuli</li> <li>Ability to follow healthy daily routines</li> <li>Engagement in – and enjoyment of – physical activities, enabled by wellfunctioning motor systems</li> </ul>	Ability to modulate strong emotions     Emotional resiliency—ability to recover from disappointment, challenging situations and move forward confidently and positively     Willingness and interest to experiment and to learn, on own and with others     A desire to create and innovate, and while doing so to use a wide range of strategies and techniques     A healthy self-esteem based on awareness of personal efforts and achievements—as well as those of others	Abilities to focus, and switch focus, as required Consider perspectives other than one's own Plan and execute several steps in a row, including trying different course of action when an initial plan has failed to work Understand cause and effect Thing logically Set learning goals Monitor and assess performance See failure as opportunity to learn Manage time effectively Develop self-awareness of strengths and weaknesses Use learning aids where appropriate	Ability to Understand their feelings and intentions Understand the feelings of others Respond to the feelings and intentions of others appropriately, both verbally and nonverbally Monitor the effects of their responses on others Be an effective communicator – as listener and speaker Demonstrate a good sense of humour that does not rely on ridicule Recover from and repair breakdowns in interactions with others	Ability to help regulate others and to coregulate with others A sense of honesty, bot with themselves and with others Empathy, or the capacity to care about others' feelings and to help them deal with their emotions Ability to put the needs and interests of others ahead of their own Desire to "do the right thing" and the conviction to act on convictions

Diving beneathe the surface in this way enables you to better pinpoint what (element/s of which particular domain/s) is/are driving the behaviour you see and are reacting to; allowing you the opportunity to respond in the way your child needs you to, instead. In this way you are able to CONNECT and forster RELATIONSHIP with your Autistic adult child in very **nurturing** ways.

#### Slide 13: Ask yourself. . .



## Reflection:

Which of the questions on this slide do you feel would be the most helpful to ask of yourself regularly when in interaction with your Autistic adult child?

#### Slides 14 - 18: Become a stress detective

The above set of slides will help you to begin to think further about what could be driving particular behaviour you have previously not been able to understand; to be able to hear possibly what was not being clearly articulated.

#### Slide 19: Consider. . .



- Stop for a moment; think of an example of distressed behaviour you observed your Autistic

- adult child display.
- Based on what you have already learnt; how would you now explain what you possibly did not understand then; what do you now think could have been driving the behaviour you observed?

#### Slide 20: Making sense of behaviour

The NICE Guidelines state that a Functional Behaviour Analysis is 'A method for understanding the causes and consequences of behaviour and its relationship to particular stimuli, and the function of the behaviour. The function of a particular behaviour can be analyzed by typically identifying (1) the precursor or trigger of the behaviour, (2) the behaviour itself, and (3) the consequence of the behaviour.'



Click on the link on the slide to read the blog, 'Functional analysis: A simple worked example of a (fictional) case' by Dr. Kate Green. At its core, functional analysis assumes that all behaviour is learned, and that all behaviours serve some purpose. This applies equally to challenging behaviours (such as violence or self-harm) as to more socially acceptable acts.

## Activity:

Draw up a template, similar to the one depicted on the slide or like the worked example template below:

GENERAL CONTEXT: This box will be involved, and materials, etc.	used to track the setting ev	rents—activity, location, people	
OBSERVER: Put your name here.	DATE and TIME: This should include the date, time and how long the occurrence lasted.		
Antecedent: What happened before?	Behaviour: What did you see or hear?	Consequence: What followed?	
In this box, you will record everything that happened immediately before the behaviour. What was the child doing? What were others doing? Where was the child, and who else was present?	What specifically happened? Who, if anyone, was the target of the behaviour? A note about the intensity of the behaviour might be included.	In this section, you will include whatever happened immediately following the behaviour. This might include environmental events or reactions of teachers, other children, and the child involved.	

Based on the knowledge you have gained and your understanding from Dr. Green's blog on Functional Analysis, conduct a functional analysis of a behaviour your Autistic adult child regularly displays, but that you are struggling to make sense of.

#### Slides 21 and 22: Reframing behaviour

This can be extremely difficult to do, especially when the observed behaviour and the impact that it has on you feels deliberate and very calculating.



Click on the link provided on slide 22 to read an article, 'The skill of re-framing' by The Centre for Parenting Education.

Simply by changing the words you use to describe your child, you can change how your child see and think about themselves and how you see and think of them.

This slide clearly depicts how an adult's/ parent-carer's mindset impacts the way they view and think about their adult child, which in turn determines how they respond to the adult child and ultimately how the adult child come's to think and feel about him/herself.

#### Slide 23: Neurodiversity: Awareness and Acceptance



This slide extends an invitation to view behaviour through a neurodiversity lens in the words of **Kristy Forbes**, an autistic support specialist for neurodivergent people and their families and professionals. You can visit her website and blog by clicking on the link provided below: https://www.kristyforbes.com.au/

#### Slides 24 and 25: Autism from the inside-out

Part 2 of this e-Learning module will begin to explore the Autistic mind. With this insight, I hope you will begin to really appreciate the invitation extended through Kristy Forbes. 'When we view behaviour through the lens of neurodiversity, we come to understand that any particular behaviour in one person can, in fact, mean something completely different in another person.'

#### PART 2

#### Slide 2: Module outline

This is an outline of the content that will be covered over the course of Part 2 of this module:

- **Neurotypes:** Neurological Differences
- **Communication:** Autism and Social Communication
- Myth Busting: Behaviour that may appear rude
- Autism and Empathy: 'Shallow' versus 'Deep' Empathy
- Theory of Mind: Perspective Taking
- Autistic Overload: Burnout, Meltdown and Shutdown
- **Masking:** Mimicking Others
- Autistic Overload: Signs of Distress
- Neurology of the Stress Response: A Physiological Reaction

#### Slide 3: Neurotypes

The essence of this slide is to highlight that 'Autism and other neurological variations may be disabilities, but they are not flaws. People with neurological differences are not broken or incomplete versions of normal people. Disability is a complicated thing. Often, it's defined more by society's expectations than by individual conditions. Not always, but often.'



Read the article, 'Clearing up Some Misconceptions about Neurodiversity: Just because you value neurological differences doesn't mean you're denying the reality of disabilities', by Aiyana Bailin. The link to the article is provided on the slide.

#### Slides 4: Neurological difference

**Neurodiversity** is a concept where neurological differences are to be recognized and respected as any other human variation. The term neurodiversity refers to variation in the human brain regarding sociability, learning, attention, mood and other mental functions in a non-pathological sense. It was coined in 1998 by Australian sociologist, Judy Singer and the concept was popularized by her and American journalist Harvey Blume.

#### Slides 5 and 6: The library is your mind

These next two slides use the analogy of a library and its many books to help us appreciate the unique way the Autistic mind processes information and makes sense of the world. This information is provided by Autistic adults in the form of a guide intended to summarize what hundreds of Autistic people around the world (speakers and non-speakers) have discovered about the atypical way their minds work, the difficulties they face daily, and how they have learned to cope with them. This guide can be accessed by clicking on the link provided on each of the above slides.

#### Slide 7: What is communication?

Being able to communicate effectively is perhaps the most important of all life skills. It is what enables us to pass information to other people, and to understand what is said to us.

Communication, at its simplest, is the act of transferring information from one place to another. It may be vocally (using voice), written (using printed or digital media such as books, magazines, websites or emails), visually (using logos, maps, charts or graphs) or non-verbally (using body language, gestures and the tone and pitch of voice). In practice, it is often a combination of several of these.

It is a two-way process. In other words, it involves both the sending and receiving of information. It therefore requires both speaking and listening, but also—and perhaps more crucially—developing a shared understanding of the information being transmitted and received.

- If you are the 'sender' of information, this means communicating it clearly to start with (whether in writing or face-to-face), then asking questions to check your listeners' understanding. You must also then listen to their replies, and if necessary, clarify further.
- If you are the recipient, it means listening carefully to the information, then checking that you have understood by reflecting back, or asking questions to ensure that you both have the same understanding of the situation.

It is, therefore an active process. There is nothing passive about communication, in either direction.

#### Slide 8: Communication and Autism

The visual on this slide is from Melanie Martinelli, The Little Black Duck, a Visual Communication Consultant, who creates individualized visuals specifically designed to support Autistic individuals develop optimal communication.

The Little Black Duck Facebook page can be accessed using the link below: https://www.facebook.com/alittleblackduck

#### Slide 9: Autism and Social Communication



#### **Reflection:**

- Read the following and consider how their meanings differ if you were to put extra emphasis on the word typed in **bold in each of the questions**:
  - What do you **MEAN**?
  - What do YOU mean?
- How do you think the prosody i.e. the rhythm of our speech, its rise and fall, energy and intonation, impact the communicated messages we convey to one another?



Read Lydia Denworth's article, 'How exactly does Autism muddy communication: The root of the **problem could be social or linguistic?**' by clicking on the link below:

https://lydiadenworth.com/articles/how-exactly-does-autism-muddy-communication/

#### Slide 10: Behaviour that may appear rude



It is, in some cases easy to identify what is and isn't rude. However when it comes to Autism this can be a different kettle of fish. This is because, whilst Autistic people are entirely capable of being purposefully impolite, there are also many aspects to our quirks which can be misconstrued as deliberately rude. As such, read James Sinclair's article, '10 "Rude" things Autistic people do (and what they really mean). You can gain access to the article by clicking on the link provided on the slide.



#### Reflection:

- Consider your own context and whether you have experienced a situation where your Autistic adult child has responded in a way that has been construed by others as rude and/or socially inappropriate.
- How has the interpretation of your adult child's behaviour impacted on the ensuing social interaction?
- How did this make you feel?
- What would you have liked to have done differently in that situation?

#### Slide 11: Autism and Empathy



In response to this slide, read the article, 'The Empathy Conundrum' from the 'Musings of an Aspie', one woman's thoughts on life on the spectrum. Click on the link provided on the slide to access this article.

An excerpt from the above article reads: 'Over and over again I see references to Autistic people having too much empathy. While I think the people using this phrase mean well, I'm not sure it's accurate. Is an Autistic person who feels overwhelmed by an emotional situation truly sharing and understanding the emotional state of another person too much or are they overwhelmed by an inability to regulate their own reaction to a highly-charged situation?'



#### Reflection:

- What are your thoughts on the issues raised in the above article?
- Do you recognize anything shared in this article that fits with your situation?

#### Slide 12: Brené Brown on Empathy

Watch the video Brené Brown on Empathy by clicking on the YouTube link provided on the slide.



#### Reflection:

- How would you explain the difference between sympathy and empathy?
- What do you think the intention is behind the response ('At least you have a marriage.') to the statement; 'I think my marriage is falling apart'?
- How would such a response, 'At least you have a marriage', make you feel?
- What would your empathetic response be to the statement, 'I think my marriage is falling apart'?

#### Slide 13: Is Autism an Empathy Disorder?



Click on the link provided on the slide to read the article, 'Is Autism an Empathy Disorder?' In this article Steve Taylor distinguishes between what he refers to as 'shallow' and 'deep' empathy. He suggests that Autism may mean a lack of 'shallow empathy,' but not 'deep empathy.'



#### **Reflection:**

'It may be that for people on the autistic spectrum, this equation is reversed: They may not be good at shallow empathy—but may not at all be impaired in terms of deep empathy.'

What are your thoughts on the above statement?

#### Slides 14 and 15: Theory of mind

Having just watched Brené Brown on Empathy, you should have noted that Empathy comprises of 4 qualities:

- Perspective taking
- Staying out of judgement
- Recognizing emotion in other people
- Communicating the emotion you recognize

Slides 14 and 15 look specifically at the first quality, Perspective taking, listed by Brené Brown, based on a study by Theresa Wiseman, a nursing scholar.



#### Reflection:

Carefully study the comic script on slide 14, why do you believe Denzel responded to his dad in the way he did?



Click on the link below to access an article by Lauren Lowry, which carefully explains what

Denzel has not get figured out and how this capacity develops in young children.

#### Slide 16: What is the Autistic Overload?

'Why does your computer suddenly choke on you? Are 1,000 windows open? Is YouTube playing while Facebook is showing cat videos? Is a browser doing some sneaky scans on the hard drive? It's all eating the data and memory. Too many tasks at once! Computer crash!

Well, imagine an autistic brain working like that. Give us too many tasks, and we'll overload! Our brains can take in a lot of details that other brains naturally filter out. These details become tasks for us to process.

Like a computer runs a software program, our brains are taking in senses and processing them. Too much input, and we shut down.'

#### By Mary Janca, self-advocate and educator

The Quote on this slide was written by **Mel Baggs**. She was very forthright in her writings and films about being a nonverbal Autistic person who made a significant impact in the fields of neurodiversity and disability rights. Of major concern to Mel was to convey that people who think and communicate in nontraditional ways are fully human, and that **humanness is a spectrum**, not something that can be reduced to a normal/abnormal dichotomy.

Many people were introduced to these ideas through Mel Baggs's short film 'In My Language,' posted on the internet in 2007. You can access the YouTube video by clicking on the link provided on the slide.

### Slide 17: Types of Autistic Overload



#### Reflection:

- Are you able to distinguish between the various types of Autistic overload?
- Can you give an example of a personal experience within in your context of:
  - Autistic burnout
  - Autistic Meltdown
  - Autistic Shutdown?

#### Slide 18: Symptoms and Causes of Autistic Burnout

Few studies have formally investigated Autistic burnout. Autism researchers have only become aware of burnout as a phenomenon over the past five years or so. They have learned about it directly through discussions with Autistic participants in person or online.

To get a little more information on Autistic Burnout you can access the article, 'Autistic Burnout, explained' by Sarah Deweerdt, a freelance science writer specializing in biology, medicine and the environment, who has made regular contributions to Spectrum News since 2010: https://www.spectrumnews.org/news/autistic-burnout-explained/

#### Slide 19: Let's talk about Masking

Many girls hide their Autism, sometimes evading diagnosis well into adulthood. These efforts can help women on the spectrum socially and professionally, but they can also do serious harm. Read the article, 'The costs of camouflaging Autism' written by Francine Russo, a veteran journalist, specializing in psychology and behavior.

The article can be accessed via the link below:

https://www.spectrumnews.org/features/deep-dive/costs-camouflaging-autism/

#### Slide 20: What masking is not

Access the article, 'What Masking is not' written by Lisa Morgan by clicking on the link provided

on the slide.

Lisa explains that 'Masking is not being someone we aren't because we don't like who we are, it's being someone we aren't because other people don't like who we are. While trying to fit into a culture that feels foreign and uncomfortable – many Autistic people, me included, were willing to hide our true selves to belong.'

#### Slide 21: Fitting in . . . Autistic Burnout

This slide reiterates a lot of what you potentially already know about Autistic Burnout, put presents it in an easily accessible way and provides us a parent-carers with some important reminders.

#### Slide 22: Autistic Meltdowns

Autistic Meltdowns are one of the most misunderstood things about Autism. A meltdown is not the same as a temper tantrum. It is not bad behaviour and should not be considered as such. When completely overwhelmed, Autistic individuals often struggle to clearly articulate this in appropriate ways. The result can lead to a meltdown. However meltdowns are not the only way an Autistic person may communicate feeling overwhelmed.

#### Slide 23: Autistic adults describe what an Autistic Meltdown feels like

Watch the video on how Autistic adults describe their experience of meltdowns. Click on the YouTube link provided on the slide

#### Slide 24: I want you to know about Autistic Shutdown



## Reflection:

- Looking at the information provided on this slide, what has struck you as particularly interesting about Autistic Shutdowns?
- If your Autistic adult experiences Shutdowns, reflect on what you can do to support him/her at these times.

#### Slide 25: While an Autistic Meltdown can be described as . . .

Click on the YouTube link on this slide to access a video which describes Autistic Shutdown from an Autistic adult's perspective.

#### Slide 26: Autistic Overload and Behaviour Problems

This slide is a concise reminder that Autism is not a set of behaviour problems, but instead a neurological difference and when overwhelmed the resultant response is often misconstrued.

#### Slide 27: Signs of Distressed Behaviour looks like



#### Reflection:

- How would you describe your Autistic adult's signs of distress?
- What specifically contributes to escalating his/her distress?
- Are you aware of how you are feeling at these times; how would you describe your feelings?
- What can help reduce his/her distress?

#### Slide 28: The Neurology of distressed response

This slide brings Part 2 of the module to an end and introduces the concept of survival mode.

The explanation below can be shared with your Autistic adult to help you both appreciate what happens to all of us when we become overwhelmed and very distressed then respond out of our innate survival mode i.e. fight, flight, freeze or fawn.

# Understanding the neurology of our distressed response to perceived threat

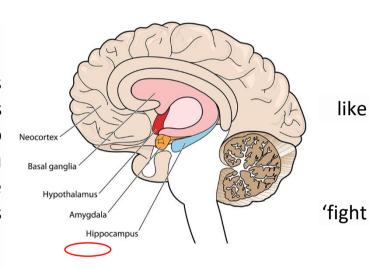


Distress is something that lots of people experience, but it feels different for everyone. Distress in children is common, and lots of adults too.

It happens because there's a part of your brain that thinks there's something it needs to protect you from. The part of the brain is called the amygdala. It's not very big and it's

shaped like an almond.

It switches on when it thinks you're in danger, so really it's your own fierce warrior, there to protect you. Its job is to get you ready to run away from the danger or fight it. People call this or flight'.

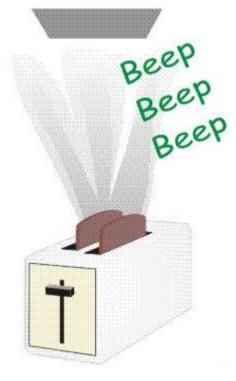


If your amygdala thinks there's trouble, it will immediately give your body what it needs to be strong, fast and powerful. It will flood your body with oxygen, hormones and adrenaline that your body can use as fuel to power your muscles to run away or fight. It does this without even thinking. This happens so quickly and so automatically. The amygdala doesn't take time to check anything out. It's a doer not a thinker – all action and not a lot of thought.



If there is something dangerous, a wild dog you need to run away from, a fall you need to steady yourself from, then the amygdala is brilliant. Sometimes though, the amygdala thinks there's a threat and fuels you up even

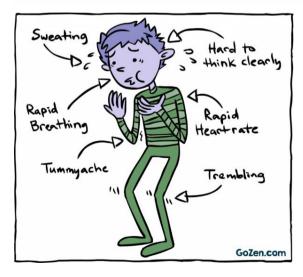
though there's actually nothing dangerous there at all.



Have you ever made toast that has got a bit burnt and set off the fire alarm? The fire alarm can't tell the difference between smoke from a fire and smoke from burnt toast - and it doesn't care. All it wants to do is let you know so you can get out of there. The amygdala works the same way. It can't tell the difference between something that might hurt you, like a wild dog, and something that won't, like being at a new school. Sometimes the amygdala iust switches on before you even know what it's switching on for. It's always working hard to protect you - even when you don't need protecting. It's a doer not a thinker,

remember, and this is how it keeps you safe.

If you don't need to run away or fight for your life, there's nothing to burn all that fuel – the oxygen, hormones and adrenalin – that the amygdala has flooded you with. It builds up and that's the reason you feel like you do when you experience distress. It's like if you just keep pouring petrol into a car and never take the car for a drive.



So when the amygdala senses a threat it floods your body with oxygen, adrenaline and hormones that your body can use to fuel its fight or flight. When this happens:

• Your breathing changes from normal slow deep breaths to fast little breaths. Your body does this because your brain has told it to stop using up the oxygen for strong breaths and send it to the muscles to they can run or fight.

When this happens you might feel puffed or a bit breathless. You also might feel the blood rush to your face and your face become warm.

• If you don't fight or flee, the oxygen builds up and the carbon dioxide drops.

This can make you feel dizzy or a bit confused.

• Your heart beats faster to get the oxygen around the body.

Your heart can feel like its racing and you might feel sick.

 Fuel gets sent to your arms (in case they need to fight) and your legs (in case they need to flee).

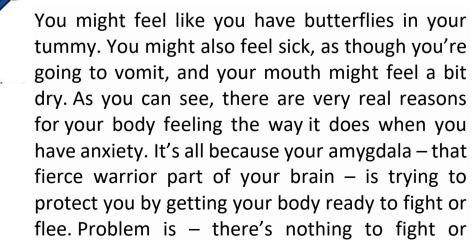
Your arms and legs might tense up or your muscles might feel tight.

 Your body cools itself down (by sweating) so it doesn't overheat if it has to fight or flee

You might feel a bit sweaty.

 Your digestive system – the part of the body that gets the nutrients from the food you eat – shuts down so that the fuel it was using to digest your food can be used by your arms and legs in case you have to fight or flee. (Don't worry though – it won't stay shut down for





flee. Don't worry though, there are things we can do about this.

#### PART 3

#### Slide 2: Module outline

This is an outline of the content that will be covered over the course of Part 3 of this module:

- Neurology of the Stress Response: Hand Model of the Brain
- Autistic Meltdown: Fight, Flight, Freeze or Fawn Response
- The Arousal Cycle: Making Sense of Distressed Behaviour
- Cause of Autistic Overload: Too much Emotional, Cognitive and Sensory Information
- Autistic Tools: Coping with Overload
- Self-Care: Parent-Carers; Me Too
- Escalating Behaviour: Responding Appropriately
- Co-Regulation: First step towards Self-Regulation

#### Slide 3: Fight/fright/freeze response

Use the link on the slide to watch the video, 'Dr Dan Siegal's Hand Model of the Brain'.



Read an excerpt from Dr Daniel Siegel's Book Mindsight: The New Science of Personal **Transformation**. This excerpt eloquently explains the hand model analogy which describes what happens to each of us when we 'flip our lids' i.e. go into fight/flight/freeze mode. Click on the link below to be able to access the excerpt from the book, Mindsight.

https://www.psychalive.org/minding-the-brain-by-daniel-siegel-m-d-2/

#### Slide 4: Responses to Autistic Overload

Whether we realize it or not, most of us are familiar with three classic responses to fear — fight, flight and freeze.

When our brains perceive a threat in our environment, we automatically go into one of these stress response modes. From an evolutionary standpoint, these responses have served us well by allowing us to respond quickly to threats and get to safety. Did you know there's actually a fourth response? It's called 'fawn'.

When threat is experienced, real or perceived, we each tend to lean toward one stress response. It's important to remember no one response is "better" or "worse" than the others. Fight looks like selfpreservation at all costs. While **flight** can look like obsessive thinking or compulsive behaviour, feelings of panic or anxiety, rushing around, being a workaholic or over-worrying, [and being] unable to sit still or feel relaxed.

Those who tend toward the **freeze** response are often mistrustful of others and generally find comfort in solitude. The freeze response may also refer to feeling physically or mentally 'frozen'. Fawning is perhaps is best understood as 'people-pleasing'. People with the fawn response are so accommodating of others' needs that they often find themselves in co-dependent relationships.

Click on the link provided on the slide to watch the YouTube video, Stress Response – Fright, flight, freeze or fawn.



#### Reflection:

- Which of the 4 stress responses would you say is your 'default' response when you feel threatened in any way?
- How would you describe your Autistic adults stress response?

#### Slide 5: The Arousal Cycle of distressed behaviour

The arousal cycle of distressed behaviour has six phases: trigger, escalation, crisis, recovery, post crisis and learning. Understanding the cycle helps us to understand our own reactions and those of others.

The **trigger phase** is when an event gets the distress cycle started. We get into an argument or receive some information that shocks us. We feel threatened at some level and our physiological system prepares to meet that threat.

The **escalation phase** is when our body prepares for a crisis with increased respiration (rapid breathing), increased heart rate and raised blood pressure, muscles tense for action, our voice may become louder or have an altered pitch, and our eyes change shape, our pupils enlarge and our brow fall. Take note of these things next time you feel distressed. Your body stance may change as well.

The **crisis phase** is when our survival instinct steps in, the fight, flight, freeze or fawn response. Our body is prepared to take action. Unfortunately, during this phase our quality of judgment is significantly reduced and decisions may be made without the benefit of the best reasoning ability.

The **recovery phase** takes place after some action has resulted during the crisis phase. The body starts to recover from the extreme stress and expenditure of energy. The adrenaline in our blood leaves gradually. Quality of judgment returns as reasoning begins to replace the survival response.

The **Post-crisis Phase** is the point when the body enters a short period in which the heart rate slips below normal so the body can regain its balance. Awareness and energy return, to allow us to assess what just happened. We may begin to feel guilt, regret or depression.

After a time the body returns to the **baseline level of behaviour** and this is referred to as the **Learning Phase**. It is during this phase that any learning / discussion can take place, but as a parent-carer be careful that the cycle does not start all over again. Sometimes it is this very discussion (experienced as an **assault** by your Autistic adult child) that can trigger another Arousal Cycle

Although the concept of The Arousal Cycle of distressed behaviour looks like a relatively simple one, a potential pitfall is lack of appreciation that some individuals can move through the cycle in a matter of minutes while others can take hours.

#### Slide 6: Emotion, behaviour, message and response: The arousal cycle of distressed behaviour

The table on this slide illustrates the emotion/s experienced during each phase of distressed behaviour; the behaviour that can be observed, the subtext of this behaviour i.e. the message of an unmet need driving the observed behaviour and finally the most appropriate parent-carer response at each phase of the cycle.

**Understanding the message of the unmet need**, which is in essence driving the behaviour, can more accurately direct the parent-carer response.

The key to preventing or reducing distressed behaviour is to recognize the observable behaviours in the Trigger and Escalation Phases and then make every effort to de-escalate the situation.

Once an individual has reached the Crisis Phase you need to be clear about what action will be taken and ensure everyone's safety.

#### Slide 7: What causes Autistic Overload

Essentially Autistic Overload is also known as autistic crises, autistic regressions and autistic overloads. It is an **involuntary physiological event** in which an Autistic person reacts to overstimulation, with partial or complete loss of self-control, including the notion of safety.

Autistic overloads vary in type, degree, and frequency, depending on each person and their sensory profile, but they are always triggered by stimulus overload, and of these stimuli the final triggers are almost always emotional stimuli.

Click on the YouTube link provided on the slide to watch the video, 'Too much information: The Aspie World - ADS Overloads'.

#### Slide 8: How heavy is your glass of water?

Click on the YouTube link provided on the slide to watch the video, 'How heavy is your glass of water?'



#### Reflection:

- How easily are you able to let go of your stress and worries?
- What sometimes makes it difficult for you to let go of a particular stress or worry?

- What self-care could you put in place for yourself, to alleviate the stress and worry you are currently experiencing?

Over the past decade the social, psychological and physical health benefits have been noted through the practice of gratitude. Access the article, 'For keeping a Gratitude Journal: Here's a way to be thankful all year long' written by Jason Marsh:

https://greatergood.berkeley.edu/article/item/tips for keeping a gratitude journal

#### Slide 9: Emotional Overload

'When worries become entrenched in our thoughts; when we stress too much and get stuck in thinking about our problems, we become exhausted, we burn out our energy, and we run out of strength to move towards solutions. This happens to everyone, even to neurotypicals.

It is all very well to be aware of the problems and to keep in mind the difficulties and the risks, but filling our head with worries for a long time exhausts us emotionally. "Let it go," "Ignore it," "Don't drown in a glass of water," "It's not that important," are complicated cognitive skills even for neurotypical people. For the autistic mind, they are impossible. Trivialization is a privilege of minds that can filter stimuli.

The autistic mind processes emotions with unusual intensity because it is holding thousands of bits of information for an extremely long period of time. Now add up the gallons that the difficulty discriminating forces us to carry, and you have a vague idea of what it feels like to be autistic. Autistic people are in a constant war with the judgment and misunderstanding of other people.'

Excerpt from Understanding the Autistic Mind: A project of the Autistic Community <a href="https://neuroclastic.com/wp-content/uploads/2020/04/UNDERSTANDING-THE-AUTISTIC-MIND-11.pdf">https://neuroclastic.com/wp-content/uploads/2020/04/UNDERSTANDING-THE-AUTISTIC-MIND-11.pdf</a>

#### Slide 10: Executive functions

Paying attention, buying bread before the store closes, choosing what you are going to eat-- they all seem like simple things to do, but each of them involves a series of high-level cognitive processes that allow you to carry them out.

Executive functions are understood as the set of skills that allow us to organize and plan for hundreds of simple ideas, movements, and actions to carry out complex tasks and adapt to the environment successfully. These cognitive processes are usually associated with the ability to filter stimuli.

Excerpt from Understanding the Autistic Mind: A project of the Autistic Community <a href="https://neuroclastic.com/wp-content/uploads/2020/04/UNDERSTANDING-THE-AUTISTIC-MIND-11.pdf">https://neuroclastic.com/wp-content/uploads/2020/04/UNDERSTANDING-THE-AUTISTIC-MIND-11.pdf</a>

#### Slide 11: Executive Function: The Brain's Control Center

Click on the link provided to access the YouTube video, 'Executive Function: The Brain's control center'.

In this video a psychologist, **Deborah Phillips**, uses the analogy to liken the Executive Functions (the control center of the brain) to an Air Traffic Control System i.e. the human capacity to manage lots of information and distractions simultaneously and the potential chaos that can ensue if some or many of these mental processes do not function as well as they should for a given activity.

#### Slide 12: Executive Functioning and Autism

Click on the link provided on the slide to access a YouTube video from Amythest Schaber, from her YouTube website, 'Neuro & Wonderful: Ask an Autistic'.

In her video she talks about executive functioning; how people use their executive functions in everyday life, what is it like to have **executive dysfunction** and how people with executive dysfunction can be supported

## Reflection:

- Having watched the two videos on Executive Functioning, which if any of the executive functions does your Autistic adult child show difficulty with?
- What are your thoughts on how you could provide support to your Autistic adult child in navigating the difficulty he/she experiences with the executive functions you have identified?

#### Slide 13: Cognitive Overload

An agile mind assimilates repetitive stimuli and learns to execute them automatically, without thinking about them, and the automation of "simple" tasks simplifies the amount of variables that an agile mind must work with. In other words, neurotypical people use their pre-judgments to make decisions quickly, and the chances of doing their best depends basically on the quality and quantity of their previous experiences.

The autistic mind, deep and detailed, perceives the micro differences between one situation and another, preventing us from assimilating them instinctively. This implies more efficient solutions even when there are no previous experiences and a high level of creativity (alternative solutions).

However, this also means that there are no "simple tasks," which increases the number of variables that must be worked with; and executing too many tasks by prioritizing, ordering, and planning in a conscious way is complicated, slow, exhausting, and consumes more energy.

It turns out that in the world we live in, the ability to do many things and do them quickly is more highlyvalued, and because of this, Autistics are often denied the time and use of resources to plan in a way that is consistent with their neurology: well and meticulously.

Research by the vast number of specialists who are focused on making Autistic children learn to "break their routines are unaware that the only thing they will achieve is to plunge them into overload. Autistic "inflexible routines" are the way Autistic people automate maintenance decisions.

Excerpt from Understanding the Autistic Mind: A project of the Autistic Community https://neuroclastic.com/wp-content/uploads/2020/04/UNDERSTANDING-THE-AUTISTIC-MIND-11.pdf

#### Slides 14 and 15: Sensory Overload



## Reflection:

Reflect for a minute or two on the statement made on slide 14: Our experience of life is woven from the information delivered by our senses.

What are your thoughts on this and how our senses (sight, hearing, taste, smell, touch, balance movement and what is going on inside our bodies) impacts our experience of life?

'All knowledge begins with sensory experience. The sense information we have accured through experience is the most personal and valid content of our minds. The thoughts and images we store in our heads originate from the experience made available to us through our senses.'

Joan Mowat Eriksan, Vital Senses: Sources of lifelong learning

Slide 15: Be mindful that someone who has a sensory seeking profile is essentially an individual who is not sensitive to certain sensory stimuli (hyposensitive response), they tend to seek more sensory stimulation to achieve an appropriate input level for stabilizing their levels of sensory arousal.

Some may people avoid sensations that they experience with excessive intensity (hypersensitivity response).

NO TWO AUTISTIC PEOPLE ARE THE SAME. THEIR SENSORY EXPERIENCES MAKE THEM UNIQUE.

How we are completely different from each other is in our perception of sensory stimuli. Each Autistic person has a different sensory profile that fluctuates between:

- Hypersensitivity and hyposensitivity
- The avoidance profile and the seeker profile
- The level of variation in how one experiences a certain sensory system.

Autistic people do not experience a consistent sensory profile; that is, it is not as simple as being a sensory seeker or a sensory avoider. Most often, it is a combination of both. We tend to be sensory seekers for certain stimuli and avoiders for others. The description of the hypersensitivities and hyposensitivities and the avoidant or seeking profiles of an Autistic person is called his or her sensory profile.

Each sensory profile is UNIQUE.

All hypersensitivities contribute to overloading the Autistic mind, and any Autistic person with hypersensitivities will be in a very high state of alert that will inevitably lead them to strong states of anxiety and burnouts.

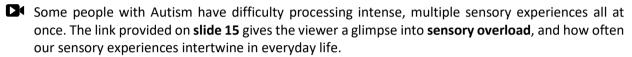
Excerpt from Understanding the Autistic Mind: A project of the Autistic Community https://neuroclastic.com/wp-content/uploads/2020/04/UNDERSTANDING-THE-AUTISTIC-MIND-11.pdf



#### **Reflection:**

As the real expert on your Autistic adult child, how would you describe his/her sensory profile based on how it fluctuates between:

- Hypersensitivity and hyposensitivity
- The avoidance profile and the seeker profile
- The level of variation in how one experiences a certain sensory system i.e. sight, hearing, taste, smell, touch, balance, movement and/or what is going on inside his/her body?



#### Slide 16: Autistic Tools: Coping with Autistic Overload

Sensory Calming Activities provide sensory input and will help your Autistic Adult child stay calm and be more able to self-regulate. Click on the link provided on this slide to access ideas of potential sensory calming activities you may find useful and your Autistic adult may experience as helpful.

Many Autstic individuals benefit from regular sensory breaks. Sensory calming activities will also help your child when they is feeling restless, distressed and/or frustrated. Sensory calming activities can also be helpful to prevent meltdowns.

#### Slide 17: Self-care is listening

As parent-carers you are your Autistic adult child's most important asset and therefore it's vitally important you look after yourselves. Reflection:



- What are you doing currently able to do to take care of yourself?
- What would you like to be able to do more of to ensure your own wellbeing?
- What steps and/or supports do you need to consider putting in place to be able to think of yourself within the context of 'me too'?

Below are some thoughts on what you could consider in terms of your own self-care:

Look after your physical and emotional health: remember your situation is a bit like the training one would need to undertake to successfully complete a marathon. Therefore whenever possible try get enough sleep, regular exercise, meditation (quiet time) and good nutrition.

Find your 'tribe': sometimes it may feel like you're the only one going through what you are currently struggling with. Locate an online or in-person support group for ASD and connect with others who understand your challenges. Some of your longest-lasting friendships will probably come this way.

Accepting limits to what you can do: ask for and accept help whenever you can and/or need to.

Take time for yourself: meet up with friends or set aside time for activities that give you pleasure, such as reading, running, or crafting.

Nurture your other important relationships: arrange a 'date' with your partner and schedule time alone with any other children you have.

#### Slide 18: Understand your contribution to escalating distressed behaviour



#### Reflection:

- Think of a recent example when a situation at home in which your Autistic adult child's behaviour escalated significantly; on reflection, what if anything did you unintentionally do to contribute to
- Were you able to at a later stage, when things had calmed down, talk with your child about what went wrong and what could be done differently next time; if so how did you experience this conversation?

#### Slide 19: The Arousal Cycle of distress: Autistic adult and Parent-carer

As parent-carers it is vitally important to be aware of yourself/each other i.e. yourself and your Autistic adult child in relation to the arousal cycle.

This slide shows how an Autistic adult (as can anyone) move through the arousal cycle as he/she becomes increasingly distressed and that parent-carers can also follow a similar arousal cycle, particularly if their capacity to cope and 'window of tolerance' is greatly reduced as a result of a whole lot of additional extenuating circumstances.

If you have a partner sharing the parent-carer role, it can be very helpful to make use of an agreed upon code word; a signal to your partner to step in so that you can for the time being, step out and in this way build g a strong tag team approach to your parenting/ caring roles.

As a parent-carer you will need to be very attuned to your own responses; as your Autistic adult's distress escalates through the various phases of the arousal cycle they will have lost the ability to self-regulate i.e. manage their own feelings and responses (their thinking brain is no longer in charge, but is offline and their behaviour is now being driven by their feeling brain).

Further more, as parent-carers when we are well attuned to our Autistic adult children and managing our own responses appropriately, we can work with our Autistic child and help co-regulate his/her behaviour and subsequently help reduce his/her levels of anxiety.



# Reflection:

- What can you do to help yourself stay attuned to your own increasing levels of anxiety and distress?
- What specifically 'hooks' you about what your Autistic adult child does/does not do when he/she begins to show signs of increasing distress?
- What do you already/could you do to help alleviate your Autistic child's distress?

#### Slide 20: An escalated adult. . .

A reminder that if you are distressed and are not able to name and/or constructively respond to how you are feeling, then you will not be in a position to support your Autistic adult child. The most helpful thing you could then consider is to temporarily remove yourself from the situation and allow yourself some time to regroup.

#### Slide 21: Responding appropriately



E Both links provided on this slide offer additional information that you may find useful in terms of what you may need to consider at times when your Autistic adult child is in crisis as well as potential strategies you could consider using to de-escalated a situation.

#### Slide 22: STOP; THINK; ACT

This is potentially a helpful strategy for you as a parent-carer to embrace. It could help you to better regulate and be attuned to your own emotions as well as to 'buy' you the necessary time to reflect on the situation and attempt to work out what it is your Autistic adult child needs so that you have a greater capacity to respond appropriately.

#### Slide 23: Attachment needing

An important reminder for every person we engage with, regardless of their particular neurotype.

#### Slide 24: The art of co-regulation

Neuroscience shows that humans develop their abilities for emotional self-regulation through connections with reliable caregivers who soothe and model in a process called 'co-regulation'. Co-regulation refers to the social relationships and the way one can adjust themselves when interacting with another, in order to maintain a regulated state. To reach a regulated state with co-regulation, a mutual adjustment of actions and intentions needs to be met by all involved.

As you are already aware, the Autistic mind processes emotions with unusual intensity; holding thousands of bits of information for extremely long periods of time. Adding up the gallons of information that the difficulty discriminating stimuli poses to the autistic mind, gives you a vague idea of what it feels like to be autistic. This is mentally exhausting and often can lead to Autistic overload, during which time an Autistic individual may experience difficulty regulating their emotions and impulses.

Co-regulation provides a practical model for parent-carers to help their Autistic children learn to better manage their immediate emotions and develop long term self-control.

#### Slide 25: Be your child's mirror

This analogy of being your Autistic adult child's mirror is an important element of co-regulation, but be mindful that this type of reflective commentary needs to be offered at the right time.

Initially, in times of distress, it is often wiser to be available, but silent.

#### Slide 26: Connecting with the thinking brain

The advice offered on this slide is very helpful in that it reminds you that before you can reason and enter into problem solving with your Autistic adult child, you need to first provide support to calm the feeling brain and connect in a meaningful way before the thinking brain can be engaged.

Exactly how you do this is very much dependent on your individual context and what strategies help your Autistic child to **feel safe**. Trust your intuition as the expert of your Autistic child in your care.

#### Slide 27: Co-regulation typically involves. . .

Access the link provided on this slide to read the blog post, 'What co-regulation looks like' by Suzanne Tucker, a physical therapist and parent educator.

**N.B.** Although the above post refers to young children the art of co-regulation is a practice that can be practiced within any relationship regardless of age and neurotype.

#### Slide 28: Further considerations. . . .

Co-regulation alone is often not enough. Autistic individuals also often need to be **actively taught** ways to exert rational control over their emotions and impulses e.g. they may need to learn verbal skills for labeling feelings and for generating rational responses.

Therefore co-regulation is the first step on the pathway to self-regulation.

#### Slide 29: Tips worth considering

Lastly further things for you to consider in how you can respond when things become challenging and you are feeling distressed.