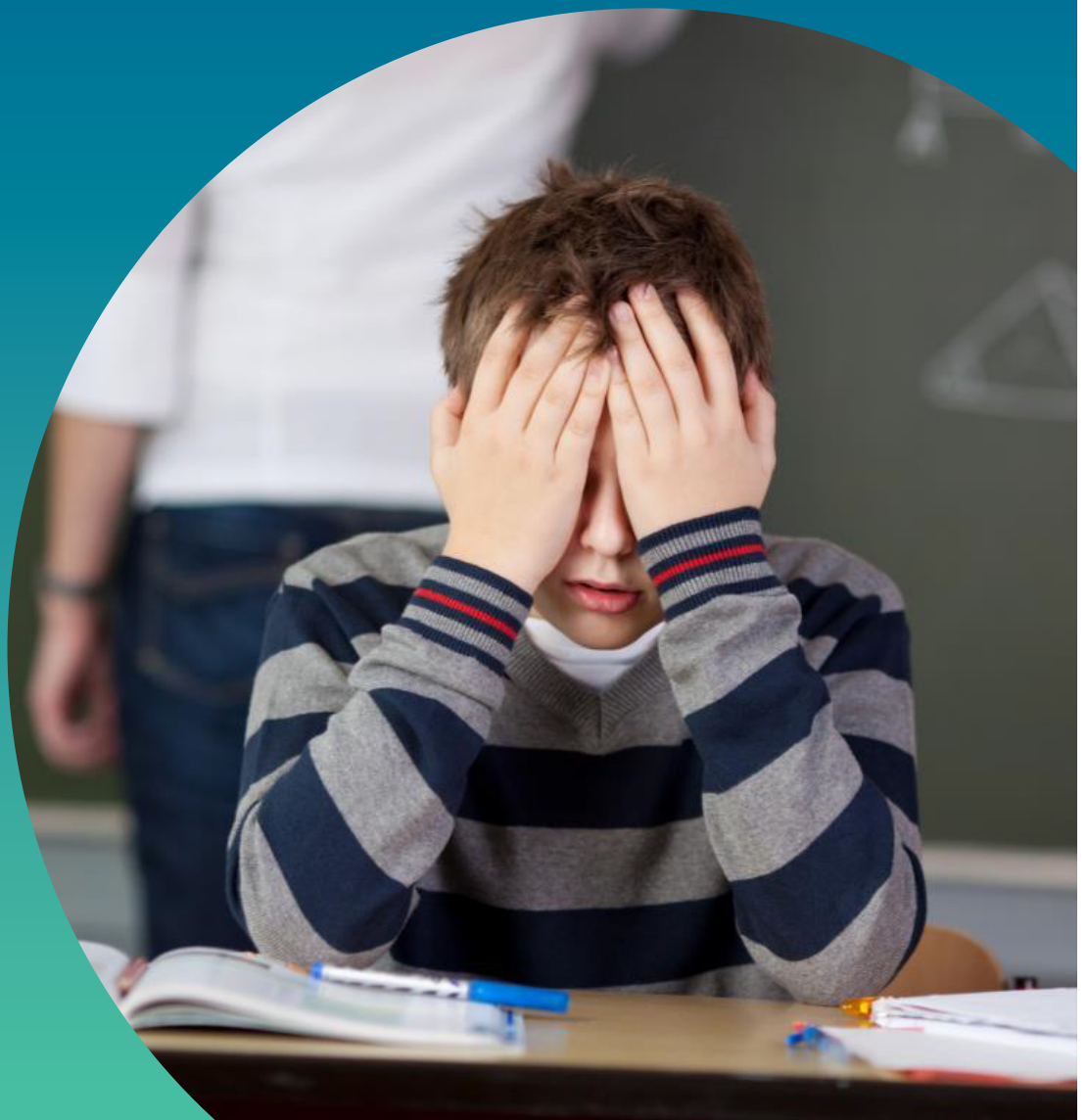




**Autism
Central**
For parents and carers

Understanding autistic overwhelm, meltdown and shutdown

A resource for parents and
carers of autistic people



Introduction

This resource is aimed at parents and carers of autistic people who want to increase their understanding of anxiety and autistic overwhelm. It provides an overview of why autistic people might experience higher levels of anxiety, what this might look like and how to support people positively.

The resource can be used as a stand-alone document for parents and carers to download and read, or as a handout for those attending the 'Understanding autistic overwhelm, meltdown and shutdown' workshop delivered by peer educators.



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Stress and anxiety

The terms 'stress' and 'anxiety' are often used interchangeably. However, they have different meanings. Below are the specific definitions of each term.

Stress is the body's reaction to feeling threatened or under pressure.

Anxiety often refers to a feeling of unease, such as worry or fear that can be mild or severe.

Anxiety becomes a clinical condition when experienced for a prolonged period of time and when it has a significant impact on a person's life

- **Anxiety is not part of being autistic**
- Autistic people can be immensely affected by anxiety, even if this is not diagnosed as a medical condition

Stress and anxiety: impact

Autistic people often report experiencing high levels of anxiety; this will have an impact on many aspects of life. Below there is a list of areas that may present as a challenge for autistic people for many reasons, including anxiety. Of course, anxiety isn't the only reason these things can be difficult and when it is the reason, it is often because there aren't any adjustments in place for the person accessing the environment.

High levels of stress and anxiety can impact on:

- Going to school/ college/ university/ work
- Spending time with other people
- Attention and focus on activities or work
- Communication
- Sleep
- Physical and mental health

"Everything new I encounter – even if it is simply the beginning of another week – is seen through the prism of fear."

Laura James

Why might autistic people appear more stressed and anxious?

Communication and interaction differences can impact on stress and anxiety.

If a person has differences in:

- Language development
- Non-verbal communication
- Their understanding of others non-verbal communication
- Processing information
- Social understanding

This can lead to feeling misunderstood by non-autistic people which provokes feelings of stress and anxiety.

Examples

Olivia is feeling sad, and she can't find her blanket. Her blanket always comforts her when she is sad. She goes to find her mum. Her brain is so anxious that it has shut down its access to language right now. Her mum says "you need to use your words." Olivia becomes very distressed as she doesn't know what to do.

Noah sings "wash, wash, wash your hands." He wants more water in his cup and he knows the song has to do with water coming out of the tap. His dad does not understand and keeps trying to make him wash his hands. Noah is confused.

Theo's friend says something incorrect and Theo bluntly replies "no, you're wrong", before explaining the right answer. But Theo's friend is more focused on the blunt words Theo has used. Theo is confused, because he thought it was helpful to show his friend the right answer, but now people are mad at him about it. Theo starts to feel anxious about talking to peers - he somehow always says the wrong thing.

Why might autistic people appear more stressed and anxious?

Dislike of uncertainty and finding security in routine

- Some autistic people thrive on routine and predictability
- It can be harder to make sense of unexpected situations and change

When a person experiences unexpected change or unpredictability, this can lead to feelings of stress and anxiety.

Examples

Esme does not mind school, as long as she knows what is coming next. After her class unexpectedly has a substitute teacher, she starts to feel anxious before school each day. What if she shows up and her teacher is gone, with no warning, again?

Felix's dad usually helps him get ready for bed. One night, he was sick and Felix's mum put him to bed instead. That was two years ago, but every night since then, Felix still asks whether his Dad is sick. He has turned asking the question into part of the routine. Asking for reassurance helps Felix deal with the anxiety of knowing first hand that sometimes unexpected things happen.



Why might autistic people appear more stressed and anxious?

Sensory differences

Many autistic people experience sensory processing differences.

Depending on the person's sensory differences, some environments may provoke feelings of anxiety or stress.

This may be because of uncomfortable or painful sensory input in that environment, for example, if you are hypersensitive to noise then taking the bus during rush hour could be difficult.

It can also be stressful if the environment is unpredictable, for example, if a person is in the park and a baby starts crying or a dog starts barking.

As well as the physical environment, some social environments will impact on a person's anxiety levels, for example, if a person is amongst people that don't understand sensory differences, or who minimise their experiences.

Examples

Arthur knows there is a fire drill at school each month. He has an over-sensitivity to auditory input and the sound of the fire alarm causes him physical pain and panic. Every time he sees the fire alarm signs in his classroom, he thinks about that sound, remembers that sometime this month he will have to hear it, and becomes anxious and sick anticipating it.

Certain food textures make Poppy gag. However, some adults have a rule that she must eat all of the food on her plate. They don't understand that it feels physically impossible for her to swallow mushy textures. They think she is being wilful and trying to avoid eating vegetables. She starts to feel anxious when she has to eat in front of others.



Masking

Masking was described by the autistic poet and author Savannah Brown as akin to, "writing and acting in a one act play at school and then writing and acting in another one act play at home".

- Masking can be described as behaving in a way that is different to who we really are, mostly because we want to fit in
- It happens consciously and unconsciously for autistic people
- It often results from fear of judgement by others
- Sometimes, masking is a survival response
- Masking is often when people internalise their needs

"How would so-and-so behave in this situation? Maybe I can mimic that."

"Am I smiling enough?
Or too much?"

"They are fine at school..."

- Autistic children will often mask whilst at school, giving the impression that everything is okay
- They may bottle up their natural responses and coping mechanisms (like stimming) and try to act in a way that will help them fit in and not draw attention to themselves
- This can be exhausting

Masking can lead to:

- Burnout
- Needing a release or even having a meltdown when back in their sanctuary at home
- Anxiety around wanting to go back to school, because they feel like no-one understands them - because no one is looking beyond the mask

Masking

Impact of masking

- Increased anxiety
- Meltdown and shutdown
- Burnout
- Difficulties in understanding and accepting their own needs and identity
- Difficulties in communicating with others, including medical professionals
- Long-term mental health implications, especially around self-worth and self-acceptance

"Since being diagnosed and understanding all of this, I am slowly finding myself again. I still mask but I actively try to do it less, so that I feel less pressure in social situations"

Charl Davies



Catastrophising

Catastrophic thinking is:

- A sign or characteristic of anxiety
- When someone always seems to see the worst-case scenario, or jump to an extreme when thinking about a situation
- A way in which the brain tries to protect itself, but it doesn't always do a very good job

Catastrophising is when you are anxious about a situation and that anxiety leads your brain to ruminate on a potentially disastrous outcome."

Purple Ella

Catastrophising

These examples show how thinking might escalate for a person who is already anxious.

Consider what that does to the anxiety levels of an already very anxious person.

We are running 10 minutes late for school

If I'm 10 minutes late for school, then I might miss something critical that makes the whole maths lesson make sense

Then I might fail the exams

If I fail the exams then I won't be able to go to the university I want to and I won't be able to get a job as an engineer like I hope

My whole life will be ruined

I want to find my favorite car toy

I did not find it in the first few seconds that I looked for it

What if it was thrown away?

What if I never see it again?

I had plans to play with that toy all day!

All of my plans for as long as I can possibly imagine are ruined, and my favorite toy is gone forever

Catastrophising

Catastrophising and anxiety

- Catastrophising and anxiety are a loop.
- Anxiety is more likely to cause catastrophising, which is more likely to cause high levels of anxiety.
- This is not a choice, but rather how the brain works.
- For young children they may be catastrophising subconsciously. Metacognition is the ability to think about your thinking, and this is a skill that only develops as humans get older.



Alexithymia

Translates as “no words for emotion”

Difficulty with identifying, describing and processing feelings and emotions

Impact of alexithymia

Difficulty in recognising anxiety may mean that:

- Anxiety levels escalate quickly
- The person has to rely on others to recognise when they are feeling anxious
- It may be difficult accessing support or they may be given the wrong support due to mislabelling emotions
- **Burnout!**



What anxiety might look like

Autistic burnout

Burnout happens when the autistic person's resources are overwhelmed

- Can be an after-effect of anxiety, but can also manifest when no anxiety has been experienced
- Can be caused by the cumulative build-up of life stressors - or a single highly stressful event
- Often misdiagnosed as chronic fatigue, depression, anxiety or bipolar disorder
- Autistic burnout is a common experience for autistic people

Autistic burnout – the signs:

These are some signs that might indicate that someone is experiencing an autistic burnout:

- Fatigue – or conversely a feeling of agitated restlessness
- Difficulty with executive function and working memory
- Sensitivity to sensory inputs and/ or an increase in sensory issues
- Increased difficulty with tasks that a person usually finds easy
- Emotional – more angry or tearful, without knowing why
- Sleeping more or less than usual
- Eating more or less than usual
- Difficulty, or lack of interest, in socialising
- Loss of interest in most things, even special interests, or a complete retreat into a particular interest
- Increase in anxiety
- Physical pain or aches



What anxiety might look like

Meltdowns and shutdowns

These are two responses to extreme stress, cumulative stress, or overload:

- **Meltdown:** a response to overload, extreme stress or cumulative stress that may involve explosive bursts of emotion and/ or a physical response
- **Shutdown:** a response to overload, extreme stress or cumulative stress that may involve withdrawal, silence and/ or immobility

Both can occur when someone feels overwhelmed by the social and/or sensory environment.

Distressed behaviour

Distressed NOT 'challenging behaviour'!

What it may look like:

- Screaming
- Biting
- Hitting
- Kicking
- Swearing
- Self-harm

Distress is not always obvious and may also lead to:

- Sleep difficulties
- Eating challenges
- Health problems
- Changes to sensory processing differences
- Ability to communicate



Supporting anxiety and distressed behaviour

Tools and tips for parents

Parents' experiences

As parents of autistic children, we can feel like the world doesn't understand. Many of the problems seem to come from an unsupportive society.

Examples of situations that might happen include:

1. A meltdown in public and at home
2. Information-overwhelm causing stress about what to do next
3. Lack of support
4. Stress from day-to-day domestic practicalities

Tools that may be helpful

Each family is unique, so some of these suggestions may be more suitable than others:

- Support groups: Talking to other parents and sharing concerns
- Self-care: Hobbies, exercises, meditation, relaxation techniques
- Therapy and Counselling: May help with coping mechanisms and stress management skills as well as a space to discuss thoughts and feelings
- Educational resources: Learning through online courses, apps books and workshops to improve understanding of autism may help empower parents in supporting and advocating for their child
- Respite care: Respite care can provide space for family members from each other, from a few hours to a day or more, if necessary.

Working with school / education settings

- Ensure that your child's school and teachers have a good understanding of autism
- Manage transitions between settings
- Talk about the things that help your child at home or school
- Discuss strengths and how to recharge energy levels
- Highlight what might trigger anxiety and discuss adjustments
- Be open when things are difficult and ask for help
- Get to know and work with your Key Worker and Family Liaison Manager
- Use clear communication

Supporting anxiety and distressed behaviour

Fears and phobias

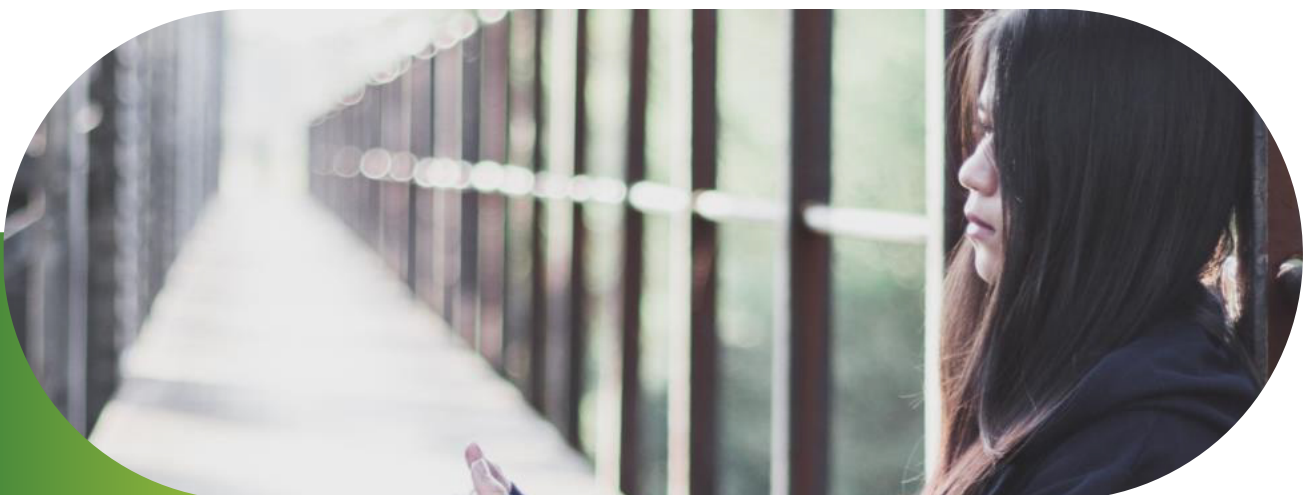
- High levels of anxiety and catastrophising often lead to fears and phobias
- Others may see these as irrational but for the person they can be very real
- Autistic people might have fears due to their differences in sensory processing, communication and social interactions
- Alexithymia might mean someone doesn't recognise or know why they have a fear

Examples:

- Avoiding crowds and social settings
- Fear of sitting near electric sockets
- Fear of being touched by others or be in close proximity to other people

Supporting fears and phobias

- It can be useful to get professional help
- Take fears seriously and ask questions to try and understand what causes anxiety
- Provide information about the situation in a way that the person prefers
- Facts and figures can work well
- Act out the situation if possible
- Provide short opportunities to experience a situation
- Incorporate interests into a new experience to help the person feel safe
- Include preferred sensory supports
- Discuss and agree an 'exit strategy' when things become too much



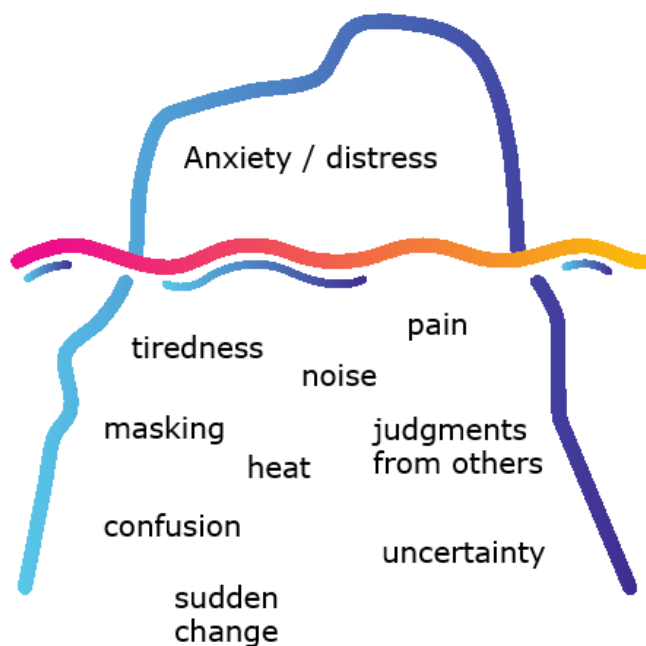
Supporting anxiety and distressed behaviour

What triggers anxiety or distress

Many people find it useful to think about the iceberg model when talking about anxiety and how to support people.

This is based on the idea that very often what we see – for example, distress and anxiety escalating – is only a very small part of a bigger picture which includes things that are not always obvious, such as the triggers of the anxiety. So, we need to look under the surface and try to identify what is REALLY happening for the person. Why are they so anxious? Why are they in distress? What do we need to avoid next time?

Sometimes the triggers or reasons are easy to identify. Maybe the person can explain these to us once they feel calmer. But there may be times that as parents or carers we need to make a note of what is happening in the wider environment when someone is in distress and try to identify a pattern. For example, if the person's anxiety escalates when in crowded environments, could it be because of the noise? If there is anxiety about being asked questions, could this be because there were too many questions or they were phrased in a confusing way? Did anxiety levels rise straight after school and the person may need a break before engaging with you?



Look under the surface!

Talk to the person when calmer

Make a note of the environment at the time

- Is there a pattern?
- What can you change in the environment?

Supporting anxiety and distressed behaviour

Preventing burnout and overload

- Self-awareness – encourage the person to understand themselves and their differences and learn from their experiences of how they react to certain situations
- Talk through any catastrophic thoughts and create assurances to reduce those concerns
- Preparation - give the person enough information about the upcoming situation
- Room to drop the mask – help reduce the energy used to mask

Energy accounting

- We all have an energy 'bank account'
- Actions or tasks can cause energy 'withdrawals'
- Energy depletion can lead to physical and mental health problems
- Energy 'deposits' replenish the energy account to 'balance the books'

Examples

Withdrawal:	Deposit:
Socialising	Solitude
Change	Zero demands
Making a mistake	Interests
Sensory sensitivity	Physical activity
Daily living skills	Animals and nature
Sensitivity to other people's moods	Meditation or mindfulness
Being teased or excluded	Computer games
	Sleep



Supporting anxiety and distressed behaviour

Approaches in the moment

When a situation escalates, it is important to try to:

- Stay calm and observant
- Understand what might be happening to the person from their point of view
- Ensure the environment is safe
- Think of the person's sensory needs and reduce sensory overload
- Reduce demands and questioning
- Use visual supports that the person is familiar with

These are also important points to take with you to a meeting at school to discuss how they plan to de-escalate in similar moments.

Think 'NEST'

The **NEST** Approach is a **4-step approach** which focuses on **supporting** autistic people in **distress**.

The aim is to **reduce the impact of meltdowns** on the person's wellbeing and the **likelihood of this happening again**.

- Nurture
- Empathise
- Sharing Context
- Teamwork

Nurture

- A meltdown can be a scary situation to be in – our focus should be on the person going through it in a safe way
- Reduce all demands from the physical and social environment and give the person time

Empathise

- Avoid judgments and try to see things from the person's point of view
- Listen

Supporting anxiety and distressed behaviour

Think 'NEST'

Sharing Context

- Problem-solve together
- Accept the person's perspective and offer other perspectives too

Teamwork

- Work together towards a solution
- Solutions need to involve everyone in the person's environment

Other considerations

- Building the person's self-esteem
- Importance of the person building their own positive autistic identity



Supporting anxiety and distressed behaviour

Key take-away messages

- Understand what causes distress and offer adjustments for these situations
- Preparation and planning may help to reduce anxiety and overload
- Meltdowns and shutdowns - try not to judge or react negatively but understand and put agreed processes in place
- Work together with institutions, such as schools, in order to understand the person and their needs in different environments
- Help build up energy deposits using preferred activities or resting choices
- Autistic meltdown, shutdown and burnout are NOT the same as experiences that non-autistic people may experience from overwhelm





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