Anxiety in ASD and the relation to sleep difficulties

• What is anxiety?

• How is anxiety different in ASD?

• How do sleep difficulties impact on anxiety and vice versa?

• How to help
Anxiety

• Far more prevalent in ASD than the general population (40-50% compared to 2-10%)

• More common than other neurodevelopmental groups, eg language impairment, Down’s syndrome, conduct disorder, learning disability

• Something very particular about ASD that leads to excessive levels of anxiety

• Underlying cause of much challenging behaviour
Societal cost of anxiety in ASD

• 142 million a year (van Steensel et al 2013)
  • ASD+AD 4x higher than AD alone
  • 27 higher than controls
• Related to lower quality of life (van Steensel et al 2012)
• Associated with high levels of self-injurious behaviour, parental stress (Kerns et al, 2015)
• Impact of anxiety often greater than the ASD itself- on child, parents, siblings
What is anxiety?

• Fear – a physiological reaction to a perception of threat
• Worry – a future-focused, cognitive process
• Stress – a demand placed on your mind or body

• Fight or flight or freeze response patterns
Why do we get anxious?

Perceived **probability of threat**  
$\times$

Perceived **cost / awfulness of danger**

Perceived **ability to cope** with danger  
$\times$

Perceived **rescue factors**
What keeps anxiety going?

**The vicious cycle of anxiety**

**Short term:** Relief

**Long term:** Increase in the physical symptoms of anxiety, more worry, loss of confidence about coping, increased use of safety behaviours

**Escape or avoidance**

**Increased scanning for danger,** physical symptoms intensify, attention narrows and shifts to self
How do we spot it?

- Arousal
- Reassurance seeking
- Avoidance
- Somatic symptoms eg changes in sleep patterns, stomach complaints, constipation, skin complaints

- Subtle changes in demeanour eg ‘freezing’, twitching
- Controlling behaviour
- Fight or flight behaviour, eg bolting, physical aggression
- Increase in obsessional/repetitive behaviours
- Verbal expression of anxiety – but may be limited even in verbally able children
When anxiety is not overtly observable

• Quiet, well-behaved child – not wishing to stand out
• Masking of symptoms – eg smiling (all the time)
• Effortful suppression of symptoms – released later in safe environment (challenging behaviour, teariness, exhaustion)

• Look out for
  • Hypervigilance/close observation of others for clues as to how to behave
  • Excessive stillness (freezing)
  • Restlessness (not attributable to ADHD)
Difference between ASD and TD population in presentation of anxiety (Kerns and Kendall, 2014; Ozsivadjian et al 2012)

• Behavioural expression of anxiety
• Prolonged, more intense, more difficult to soothe
• Specificity of worries around change, routine (in the absence of generalised worry)
• Unusual specific fears eg babies crying, happy birthday song
• Social fearfulness (in youth who lack an awareness of social judgement)
Pathways to anxiety in ASD

• Cognitive – intolerance of uncertainty, cognitive rigidity, attentional bias, executive function impairments, theory of mind?
• Neuroanatomy/neurophysiology/neurobiology
Intolerance of ...more than uncertainty?

• Of discomfort?
  • Of internal state
  • Of external stimuli
Emotional regulation

• Emotional response/reactivity requires emotional regulation

• ER defined as efforts to modify or control the intensity of an emotional reaction, usually in the service of an individual goal (Thompson, 1994).
  • Reappraisal, problem-solving

• Emotional dysregulation may present as:
  • ‘Meltdowns’
  • Irritability
  • Aggression
  • Self-injury
  • Impulsivity
  • Suppression, rumination
  • And anxiety
Chicken and egg

• Anxiety and worry can impair sleep

• Poor sleep can cause irritability and reduced cognitive function, apathy and impaired emotion regulation

• Which can cause anxiety.....

• Not to mention disruption of the sleep of everyone else...

• Which can result in fewer resources to manage challenging bedtime behaviour...
Research evidence of the relationship between sleep and anxiety in the general population

eg Chorney et al (2008)

• Significant relationships have been found between sleep problems, anxiety and depression in the typically developing population

• The interplay between these can create a perpetuating cycle

• Targeting one problem may indirectly affect another – eg targeting separation anxiety may reduce bedtime struggles, night time waking
Research evidence of the relationship between sleep and anxiety in ASD

• Sleep problems and anxiety are significantly correlated in ASD/ID, and contribute hugely to challenging behaviour – sleep problems stronger predictor than anxiety (Rzepecka et al, 2011)

• Improvements in sleep over time were associated with improvements in anxiety (Fletcher et al, 2017)

• More maladaptive activity at bed time related to sleep onset time. (“)
Research evidence of the relationship between sleep and anxiety in ASD ctd.

- Internalising problems (withdrawal, somatic complaints, fearfulness) predicted sleep related problems more than social deficits, externalising symptoms and anxiety symptoms (Madeau et al, 2015)
- Disordered sleep is associated with cognitive performance and behavioural problems in ASD (Astill et al, 2012)
- Sensory Oversensitivity and anxiety strongly related to sleep problems (Mazurek and Petroski, 2014) – hyperarousal at a brain level?
So what can we do?

- First crucial step – understand why your child is anxious. If they can’t tell you....
Functional assessment

• A process to establish patterns of behaviour
• Identify why a behaviour is happening and what might be maintaining it
• Evidence gathering and hypothesis testing
• Permits individualised treatments

• Particularly useful when people can’t tell us what they are feeling, but they can show us
What you can try at home

• Practical strategies to help your child relax – prevention is better than cure
• Increasing emotion awareness and regulation
• Be aware of reinforcing anxiety– balance protection with promoting resilience
• Model non-anxious behaviour
The basics

• Diet, sleep, **exercise**
• Special time 1:1
• ALL CHILDREN NEED **DOWN TIME**
• Have routines when you can
• Play to child’s strengths
• Push for new things, but slowly and gently
• Be alert for teasing and bullying...
Think about our reactions to child’s anxiety

Adaptive protection

Excessive protection
Learn facts about anxiety....

- Anxiety is normal
- Makes your heart race/tummy hurt/headache etc
- Affects the way you think
- Can’t be turned off quickly—eventually subsides by itself
- Can be fun for some (eg rollercoasters, scary films)
- Is rarely harmful
Emotion awareness

• Identify emotions
• Rate emotion intensity
• Model your own emotions
• Express emotions
• Learn to measure anxiety – catch it in the early stages
What can we try?

LOST THE PLOT!

10
9
8
7
6
5
4
3
2
1

I'm feeling very worried!

I'm feeling very worried and I'm starting to lose control...

I'm feeling more worried about

I'm starting to feel a little worried about...

I'm cool, calm and in control
Emotion regulation skills

• Prevention – healthy eating, sleeping, physical activity
• Focus on strengths
• Use your words
• Write it down
• Who to share with? when? Why is this important? (emotional support, help with problem-solving
• Does it matter? How important is the feeling? Getting things in perspective
Thinking skills

• A thought is just a thought
• Try and stop ‘what if?’ thinking (give it a name, like ‘rollercoaster thinking’, or ‘messages’, or whatever language is meaningful to your child)
• Think ‘is this a problem or a worry?’ If it’s a problem, solve it!
• Schedule in worry time – for some people their worries dry up when they actually have to worry!
• Have a worry box
Environmental modifications

• Structure environment to support thinking
• Increase predictability to aid comprehension
• Give clear explanations – not just ‘because I say so’
• Visual principles
  • Visual timetables (what, where, when)
  • Social stories (why and how)
Predictability/ routine

Joe's Schedule (an example of a visual schedule)

- math class
- recess
- art class
- lunch
- reading class
- bus

Today:
1. get dressed
2. drive to work
3. work
4. go home
5. read

Our schedule will probably be:

[Visual representation of a schedule with icons and numbers]
Predictability/ routine

Surprise
The noise you hear is a fire alarm.

It is OK. Get in line behind me.
Tips to help the child relax

- Physical exercise
- Belly Breathing
- Counting
- Thinking of pleasant situations (i.e. their favourite train)
- Gentle physical touch (hugs, squashing ball)
- Repetitive behaviours

Rezone App
The role of school

• Can small changes make a difference? Worry about the next day at school can have a huge impact on school.
  • Meet and greet
  • Modified homework expectations
  • Later/earlier entry to school to avoid crowds
  • Having a go-to person
Psychological treatments

• Adapted CBT – including imagery restructuring, targeting intolerance of uncertainty and cognitive remediation therapy
• Mindfulness - may be more helpful in reducing maladaptive strategies such as rumination and suppression, improve baseline arousal levels
• Dialectical Behaviour Therapy
• Interventions delivered within school settings eg STEP-ASD, Facing your Fears