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**

\[ \times \]

Perceived **ability to cope** with danger

\[ \times \]

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

The vicious cycle of anxiety

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

Increased scanning for danger, physical symptoms intensify, attention narrows and shifts to self

Short term: Relief

Escape or avoidance
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/tuny hurt/head ache 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, 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)

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

<table>
<thead>
<tr>
<th>Today</th>
<th>our schedule will probably be:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joe's Schedule</td>
<td></td>
</tr>
</tbody>
</table>
Predictability/ routine
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