

Understanding and managing Sleep problems for children
and young people with complex co-morbidities including
ASD, ADHD and intellectual disability.

Dr Gemma Batchelor

Consultant general and community paediatrician

Sleep problems for CYP with neurodiverse conditions or intellectual disability.

- Children with neurodevelopmental disorders frequently have less than optimal sleep.
- Significantly higher rates than the general population. This occurs in around 50-80%
- The severity of the underlying disorder is a predictor of sleep problems



Chronic mild sleep deprivation can be associated with:

- Emotional instability
- Decreased pain tolerance
- Metabolic disease
- Immunodeficiency
- Impaired cognitive function

- This will often impact negatively on their functioning and development.
- It is vital to ensure a sufficient amount of good quality sleep is achieved.



How does this present?

- Common difficulties include:
 - difficulty falling asleep
 - frequent night time wakening
 - fragmented sleep
 - early wakening “ready to go”



What contributes to sleep problems?

- Over-arousal - fear/anxiety, insecure attachment, sensory dysregulation
- Less responsive to environmental cues/social expectations
- Maladaptive learning - co-sleeping,
- Physical factors - pain, incontinence, restless legs (ferritin levels)
- Mental health conditions
- It is crucial to exclude any underlying medical causes such as sleep apnoea, GOR and seizures



Comprehensive assessment



- What is the sleep problem?
- Current day and night sleep patterns
- What is the sleep environment like? TV/gadgets, toys etc
- Is there an established regular bedtime routine?
- Levels of activity/exercise during the day
- Possible physical/medical causes to disrupt sleep
- Effects of any medication
- How sleep disturbance is impacting carers and other family members



Intervention



Behavioural approaches

- Current guidelines recommend parent-directed behavioural sleep interventions as first line treatment for sleep difficulties, with reportedly a 25% response rate.
 - Health-visitor - Sleep Scotland training
 - CAAS - sleep webinars [Early Help for Parents & Carers](#)
- Working with parents to establish a sleep plan
 - routine, eating and drinking, exercise and activity, , timing, bedroom environment, sleep associations, background sounds and screen time

Pharmacological intervention


- Pharmacological intervention should only be considered when
 - Sleep difficulties persist despite following the sleep plan
 - Sleep disturbance is having a negative impact on the CYP, carers or family



Melatonin

- The chemical expression of darkness - when it is dark outside this results in a chemical message being sent to the pineal gland which releases melatonin.
- Naturally released amounts are smaller at $<0.3\text{mg}$.
- It can be used as
 - a hypnotic agent to induce sleep
 - a chronobiotic agent to try and shift the sleep wave cycle slightly forward/back.
- In practice we tend to use it as a hypnotic agent
 - To induce sleep when the persons homeostatic drive to induce sleep is insufficient or inhibit the drive for wakefulness during the wake propensity phase of the circadian cycle.



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- Melatonin has a clearly established place in management of sleep difficulties in children with ASD and ID
 - Melatonin should never be a “stand alone” solution and should always be accompanied by behavioural interventions.
 - A melatonin treatment holiday should be attempted regularly as efficacy of melatonin may be lost if prescribed for longer than two years continuously.
 - Reinforcement of good sleep hygiene should be discussed at each review and should be continued by the child / adolescent in conjunction with melatonin prescribing.



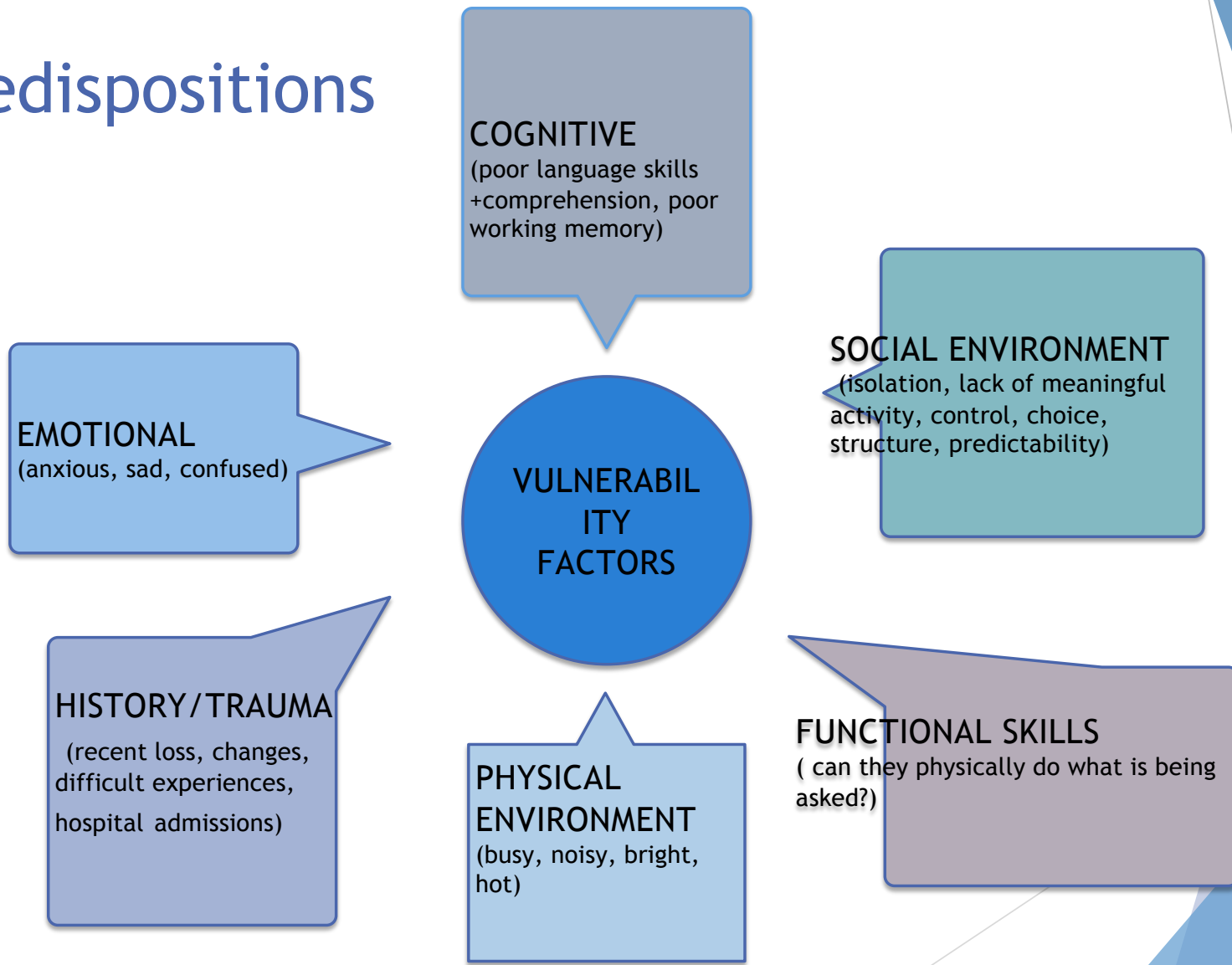
Challenging Behaviours

Hannah Todd ST5 Paediatrics

What is Challenging Behaviour?

- Behaviour is described as challenging when it is of such **INTENSITY, FREQUENCY** or **DURATION** as to threaten **QUALITY OF LIFE** and/or **PHYSICAL SAFETY** of the individual or others. And is likely to lead to responses that are **RESTRICTIVE, AVERSIVE** or result in **EXCLUSION**, affecting everyday ability to **LEARN** and **DEVELOP**
 - **Aggression:** verbal and physical, destruction to property
 - **Withdrawal:** including wandering off unsupervised
 - **Self injurious:** headbanging, suicide
 - **Refusing to cooperate:** food refusal
 - **Temper tantrums/defiance**
 - **Restricted and repetitive behaviours**
 - **Inappropriate behaviours:** alcohol excess, sexualised behaviours
 - **Staying awake at night**

Predispositions



What Causes Challenging Behaviour?

- Form of communication: struggle to verbally communicate their needs
- Lack cognitive understanding of their environment
- Lack control over choices/needs/wants/what happens
- Pain or discomfort as a result of physical problems: eg ear ache
- Sensory processing differences: noise/light/spatial awareness of bodies
- Reaction to change or unfamiliar situations or events
- Uncomfortable in social situations: meeting new people or look people in the eye
- Functionally: Asked more than they can manage/lack motivation/desire
- Want something they can't have, such as a toy
- Tired, unwell, fed up or just having an 'off day'



Management of Challenging Behaviour

- Parents can find it difficult to understand their child's behaviour
- There is always a reason for challenging behaviour
- Try to see behaviour as a form of COMMUNICATION
- Looking for patterns of behaviour, we can gain clues as to how to manage it
- Prevention the best solution

- Think 'STAR' when history taking:
 - **SETTING:** Where did the behaviour occur? crowded/noisy...
 - **TRIGGER:** What happened immediately before
 - **ACTION:** What was the behaviour exactly
 - **RESPONSE:** How did you or others respond

Management of Challenging Behaviour

- NICE Guidelines
 - Annual physical health check of CYP with a learning disability
 - Useful to use a standardised template: Cardiff health check template
- Support parents and CYP to develop an understanding of the reasons behind challenging behaviour: this is imperative to assist change in behaviour
 - Health-visitor
 - School
 - Child and Adolescent Autism service (CAAS)
 - Children's disability service
 - CAHMS

Child and Adolescent Autism Service

- Provide support for children, young people and their families following an autism diagnosis
- Developed an interactive online resource that includes advice, helpful strategies and training
 - <https://view.pagetiger.com/prediagnosticresources/1>
- Directory of services which includes information and contact details for other organisations that can provide help and support.
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Children's Disability Service

- Support provided by a range of teams
 - **Community Teams**, which include social workers and learning disability nurses, provide specialist advice and support
 - **Children's Interdisciplinary Schools Team** provides a service in schools to children who are having difficulty accessing the curriculum.

