The Cerebra Network for Neurodevelopmental Disorders

The Baily Thomas Charitable Fund

UNIVERSITY OF BIRMINGHAM

Richards Lab Birmingham

2021 E-WEBINAR SERIES

TAND

SLEEP

PRESENTED BY: GREENWICH BIOSCIENCES

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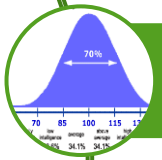
@BissellStacey

https://www.cerebranetwork.com/

SLEEP IN THE CONTEXT OF TSC

Epilepsy



Intellectual disability (ID)

Attention deficit hyperactivity disorder (ADHD)

Autism

Poor sleep is prevalent

SPECIAL ARTICLE LEVEL OF RECOMMENDATION

Practice guideline: Treatment for insomnia and disrupted sleep behavior in children and adolescents with autism spectrum disorder

Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology

Nature and Science of Sleep

Dovepress

open access to scientific and medical research

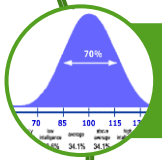
Open Access Full Text Article

REVIEW

Sleep disorders in patients with ADHD: impact and management challenges

SLEEP IN THE CONTEXT OF TSC

Epilepsy



Intellectual disability (ID)

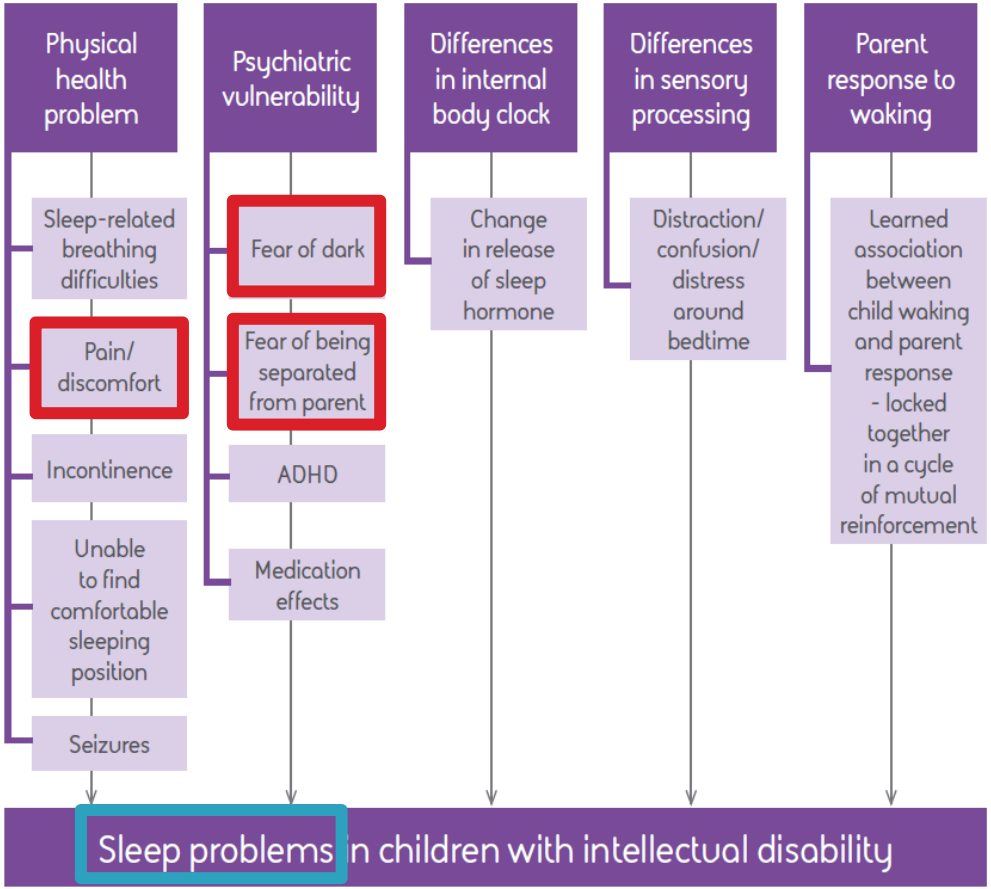
54-99%

Attention deficit hyperactivity disorder (ADHD)

Autism

- Insomnia
- Excessive Daytime Sleepiness
- Sleep-Related Breathing Disorders
- Parasomnias
- Sleep-Related Movement Disorders
- Circadian Rhythm Disorders

IMPORTANT SLEEP CONSIDERATIONS



Rely on parent report

Rely on self-report

Agar, Trickett, Oliver, & Richards, C. (2017). Sleep: A guide for parents.

METHODS OF SLEEP ASSESSMENT

SUBJECTIVE MEASURES

- Self-report questionnaires
- Parent report questionnaires
- Sleep diaries

Sleep Diary

CEREBRA
Working wonders for children with brain conditions

Child's Name: Parent/ carer's Name:

Date							
Time of waking in morning							
Mood upon waking							
Times of naps during the day							
Time started preparing for bed							
What time did the child go to bed?							
What time did the child get to sleep?							
Time(s) of waking during the night (e.g. 2:30am, 4am etc...)							
What did you (parent/ carer) do?							
Length of time(s) taken to fall asleep again							
Total no. of hours sleep							

OBJECTIVE MEASURES

Actigraphy	Watch-like device placed on wrist or ankle that detects movement as a proxy measure for sleep and wakefulness
Polysomnography	Electrodes placed on scalp and face throughout sleep duration
Videosomnography	Time-lapse methods used to record and score sleep behaviours

SYNDROME-SPECIFIC FACTORS RELATING TO SLEEP

RESEARCH Open Access

Sleep disorders in rare genetic syndromes: a meta-analysis of prevalence and profile

Georgie Agar[1*], Chloe Brown[1,2], Daniel Sutherland[1], Sean Coulborn[1], Chris Oliver[1] and Caroline Richards[1]

Table 6 Clinical summary of elevated and equivocal risk for each type of sleep disorder in each syndrome

Syndrome	Sleep-related breathing difficulties	Insomnia	Excessive daytime sleepiness	Sleep Enuresis	Sleep bruxism
Angelman	+	++	+	++	+
CHARGE	++	–	–	–	–
Cornelia de Lange	++	++	+	–	–
Cri du Chat	–	–	–	–	–
Down	++	++	+	+	++
Fragile X	++	+	+	++	++
Hurler	++	–	–	–	–
Jacobsen	–	–	–	–	–
Juvenile Neuronal Ceroid Lipofuscinosis	–	–	–	–	–
Mucopolysaccharidosis Type II	++	–	–	–	–
Mucopolysaccharidosis Type IIIB	+	–	–	–	–
Mucopolysaccharidosis Type IVA	++	–	–	–	–
Neurofibromatosis	+	++	++	–	–
Prader–Willi	++	+	+	+	–
Rett	+	++	+	–	+
Smith–Magenis	–	+	++	–	–
Smith–Lemli–Opitz	–	–	–	–	–
Tuberous Sclerosis Complex	–	++	++	–	–
Williams	++	++	+	+	+

++ indicates a sleep disorder which should be considered as part of a priority assessment in that syndrome, + a sleep disorder which should be considered as part of routine assessment, and – a sleep disorder where further research is needed

CLINICAL RECOMMENDATIONS

The UK guidelines for management and surveillance of tuberous sclerosis complex. *QJM: An International Journal of Medicine*, *112*(3), 171-182.

(Amin et al., 2019)

Surveillance for neurodevelopmental and Neuropsychiatric disorders	
At each annual clinical review, the TAND check list should be used	Consensus
In-depth neuropsychology and neuropsychiatric assessments should be undertaken when indicated	Consensus
Treatment should follow the NICE guidelines	Expert opinion
Developmental status should be formally evaluated at key developmental time points and periods of transition, which are infancy (0–3 years), preschool (3–6 years), middle school (6–11 years), adolescence (12–18 years), and as clinically indicated	Consensus
TSC clinics should have established links and care pathways with developmental paediatric, educational and CAMHS specialist services to help ensure a seamless, integrated, responsive and timely multidisciplinary approach, which includes consultation and liaison	Expert opinion

CLINICAL RECOMMENDATIONS

THE **TAND** CHECKLIST

Lifetime version (TAND-L)

Tuberous Sclerosis Complex (TSC) is associated with a range of neuropsychiatric disorders which we re to as **TAND** (**TSC**-**A**ssociated-**N**europsychiatric-**D**isorders). All people with TSC are at risk of having some of these difficulties. Some people with TSC have very few, while others will have many of them.

Each person with TSC will therefore have their own TAND profile, and this profile may change over time. This checklist was developed to help clinical teams, individuals with TSC and their families a) *screen for TAND at every clinic visit* and b) *prioritize what to do next.*

Instructions for use

The TAND Checklist was designed to be completed by a clinician with relevant knowledge and experience in TSC, *in partnership* with individuals with TSC or their parents/carers.

The Checklist should take about **10 minutes** to complete.

Where individuals answer **YES** to an item, the clinician should explore the difficulty in sufficient detail to help guide decisions about further evaluation or treatment. **All items should be completed.**

About the interview

Name of TSC Subject: ..... DOB: d d/m m/y y Age:

Name of Interviewer: ..... Date of interview: d d/m m/y y

Name of interviewee: ..... Self / Parent / Carer / Other *(circle)*

Let's begin

As you will know, the majority of people with TSC have some difficulty in learning, behaviour, mental health, specific aspects of their development and so on. We are going to use this checklist to help us check for these kinds of difficulties. I am going to ask you a number of questions.
Some may be directly relevant; some might not be relevant at all. Just answer as best as you can.
At the end I will check to see if there are any additional difficulties we didn't talk about.

For parents/carers of individuals with TSC, please start with question 1.
For individuals with TSC who complete this about themselves, please start with question 3.

01 Let's begin by talking about [subject]'s development to get a sense of where they are at. How old was [subject] when he/she:

a. First smiled?	Age:		Not yet:	
b. Sat without support?	Age:		Not yet:	
c. Walked without holding on?	Age:		Not yet:	
d. Used single words other than "mama" or "dada"?	Age:		Not yet:	
e. Used two words/short phrases?	Age:		Not yet:	
f. Was toilet trained during the day?	Age:		Not yet:	
g. Was toilet trained at night?	Age:		Not yet:	

Sleep Diary

Child's Name: Parent/ carer's Name:

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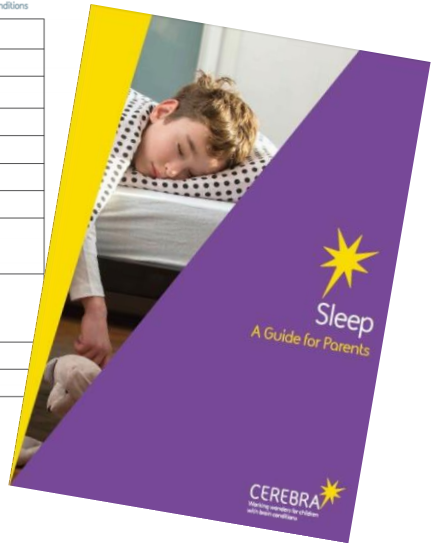

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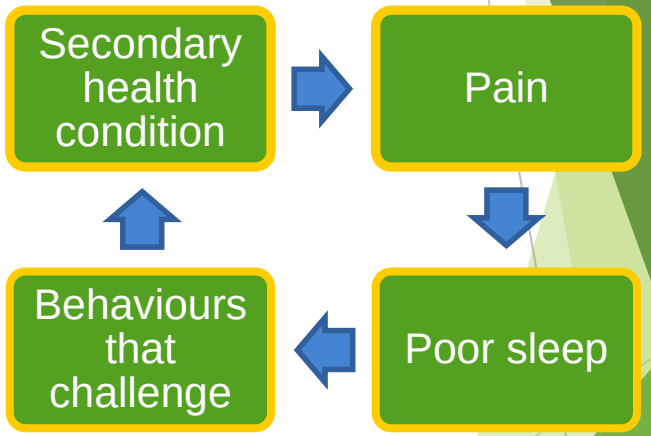
Secondary health conditions

NICE National Institute for Health and Care Excellence

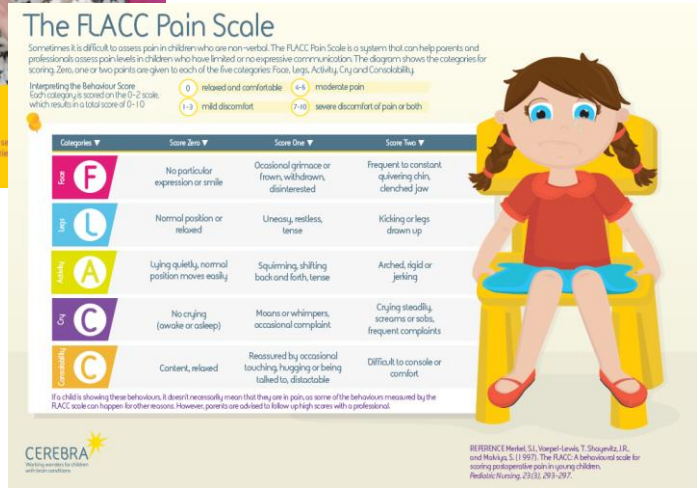
Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

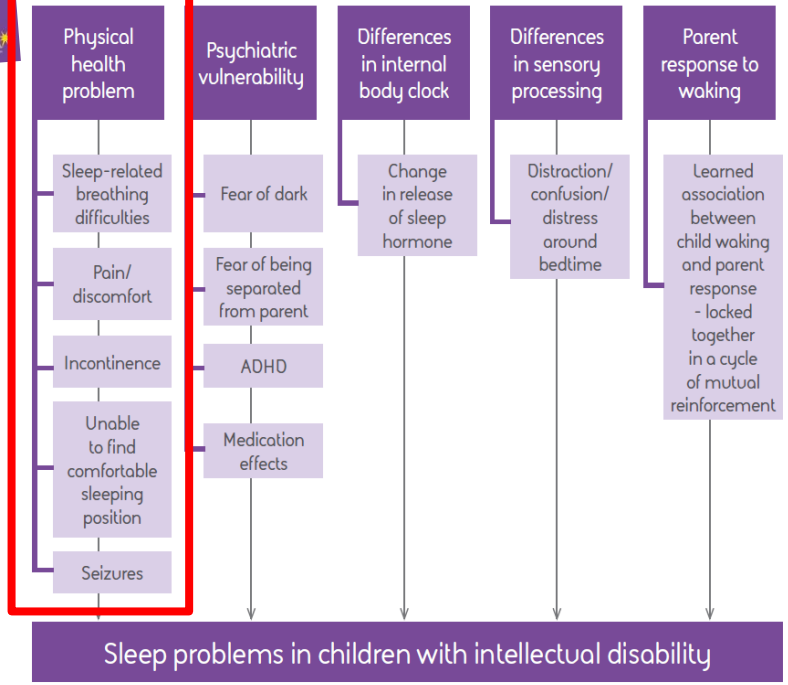
NICE guideline [NG11] Published date: May 2015 Uptake of this guidance

1 Recommendations



Secondary health conditions

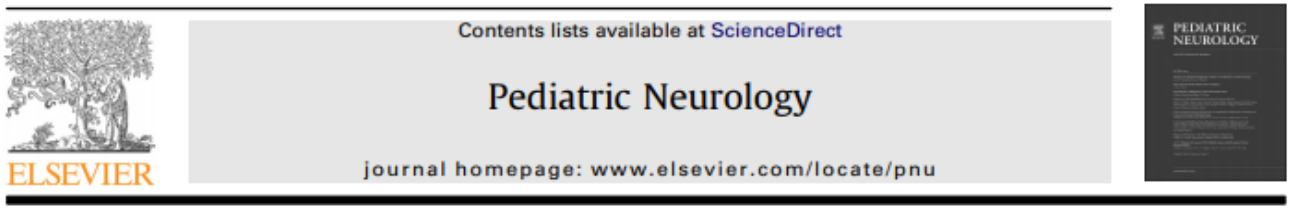




Take home messages so far …

- There are several co-occurring factors prevalent in TSC where we know sleep may be affected
- Several of these co-occurring factors may be difficult to assess in individuals with TSC
- There are subjective and objective measures of sleep – there are costs and benefits of both
- The profile of sleep difficulty in TSC may have some overlap with other syndrome groups, but same may be specific to the co-occurring factors we see in TSC
- **It is important to measure pain as a factor contributing to poor sleep**

TSC ASSOCIATED NEUROPSYCHIATRIC DISORDERS (TAND)



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Pediatric Neurology

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The term ‘TAND’ (TSC Associated Neuropsychiatric Disorders) was coined (Krueger et al., 2013a)

Approximately 90% of individuals with TSC evidence features associated with TAND at some point during their lifetime (Curatolo, Moavero, & de Vries, 2015)

However, only 20% of individuals receive assessment/treatment for TAND (de Vries et al., 2018)

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TOSCA REGISTRY

Tuber**O**us **SC**lerosis registry to increase disease **A**wareness **(TOSCA)** – baseline data on 2093 patients (Kingswood et al., 2017)
TSC-associated neuropsychiatric disorders (TAND): findings from the TOSCA natural history study (de Vries et al., 2018)

TAND Features	Individuals With Manifestation, n (%)	Individuals With Available Data, n (%)	Individuals with Data Not Available, n (%)
Behavioural level			
Overactivity	337 (45.0)	749 (33.8)	1467 (66.2)
Sleep difficulties	331 (43.9)	754 (34.0)	1462 (66.0)
Impulsivity	317 (42.7)	742 (33.5)	1474 (66.5)
Anxiety	240 (33.3)	720 (32.5)	1496 (67.5)
Mood swings	214 (29.8)	718 (32.4)	1498 (67.6)
Severe aggression	183 (24.3)	754 (34.0)	1462 (66.0)
Depressed mood	139 (19.2)	724 (32.7)	1492 (67.3)
Self-injury	117 (15.5)	755 (34.1)	1461 (65.9)
Obsessions	100 (14.0)	714 (32.2)	1502 (67.8)
Psychosis	40 (5.5)	725 (32.7)	1491 (67.3)
Hallucinations	26 (3.6)	719 (32.5)	1497 (67.5)

(de Vries et al., 2018)

No available data on these behaviours at baseline

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(de Vries et al., 2018)

- Higher levels in children ≤ 18 years
- Higher levels in adults > 18 years

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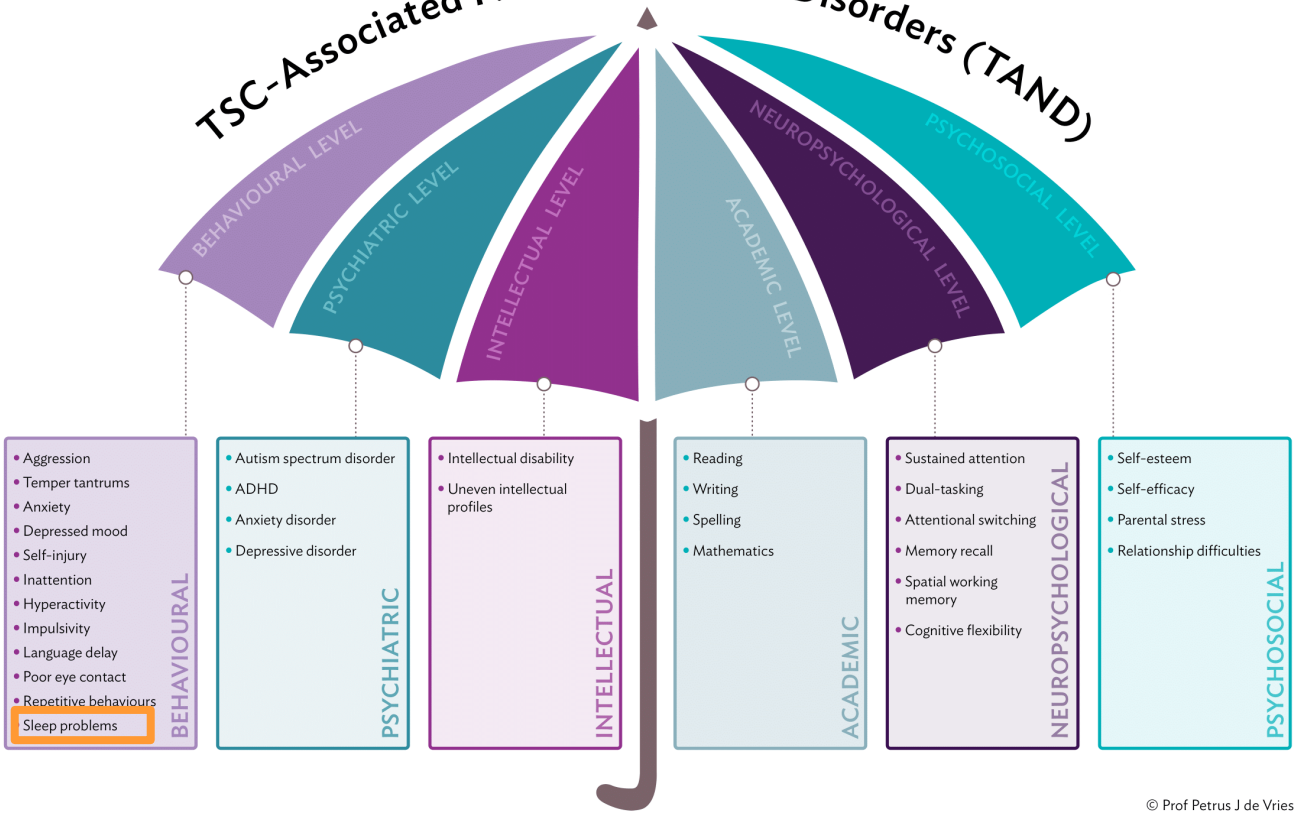
SLEEP IS A TAND BEHAVIOUR

TANDem
Empowering families through technology



SLEEP IS A TAND BEHAVIOUR

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Empowering families through technology

HOME ABOUT RESOURCES TEAM PARTNERS TIPS CONTACT

Cluster group	Members
Autism spectrum disorder-like cluster	Nola Chambers (lead), Jamie Capal (co-lead), Eva Schoeters, Sebastián Cukier, Shoba Srivastava
Dysregulated behaviour cluster	Tanjala Gipson (lead), Peter Davis (co-lead), Agnies van Eeghen
Eat/sleep cluster	Stacey Bissell (lead), Katie Smith (co-lead), Peter Davis
Mood/anxiety cluster	Agnies van Eeghen (lead), Jamie Capal (co-lead), Megumi Takei, Robert Waltereit
Neuropsychological cluster	Anna Byars (lead), Jennifer Flinn (co-lead), Vicky Whittemore
Overactive/impulsive cluster	Robert Waltereit (lead), Stacey Bissell (co-lead), Katie Smith, Megumi Takei
Psychosocial cluster	Chris Kingswood (lead), Stephanie Vanclooster (co-lead), Eva Schoeters, Katie Smith, Sebastián Cukier, Vicky Whittemore
Scholastic cluster	Jennifer Flinn (lead), Dena Hook (co-lead), Jamie Capal, Peter Davis, Shoba Srivastava

SLEEP MAY UNDERLIE OTHER ASPECTS OF TAND

Trickett *et al. Journal of Neurodevelopmental Disorders* (2018) 10:9
https://doi.org/10.1186/s11689-018-9226-0

Journal of
Neurodevelopmental Disorders

RESEARCH Open Access

A cross-syndrome cohort comparison of sleep disturbance in children with Smith-Magenis syndrome, Angelman syndrome, autism spectrum disorder and tuberous sclerosis complex

J. Trickett[1,2*], M. Heald[2], C. Oliver[2] and C. Richards[2]

- Children with TSC evidencing **gastro-oesophageal reflux** obtained higher sleep onset latency and night waking scores
- Night waking and parasomnia scores were positively correlated with **overactivity** scores in children with TSC

Table 6 Profiles of sleep disturbance in children with ASD, SMS, AS and TSC compared to TD children

	AS	SMS	TSC	ASD
Sleep anxiety	–	O	O	O
Bedtime resistance	O	O	O	+
Sleep onset latency	O	O	+	++
Night waking	++	++	+	+
Sleep-disordered breathing	+	++	O	+
Parasomnias	+	++	+	+
Daytime sleepiness	++	++	+	+
Severe early morning waking problems	++	+++	+	++

O effect size $r < 0.2$, + small effect size r 0.20–0.49 or odds ratio 0.2–9.0, ++ medium effect size r 0.5–0.8 or odds ratio 10.0–49.0, +++ odds ratio > 50

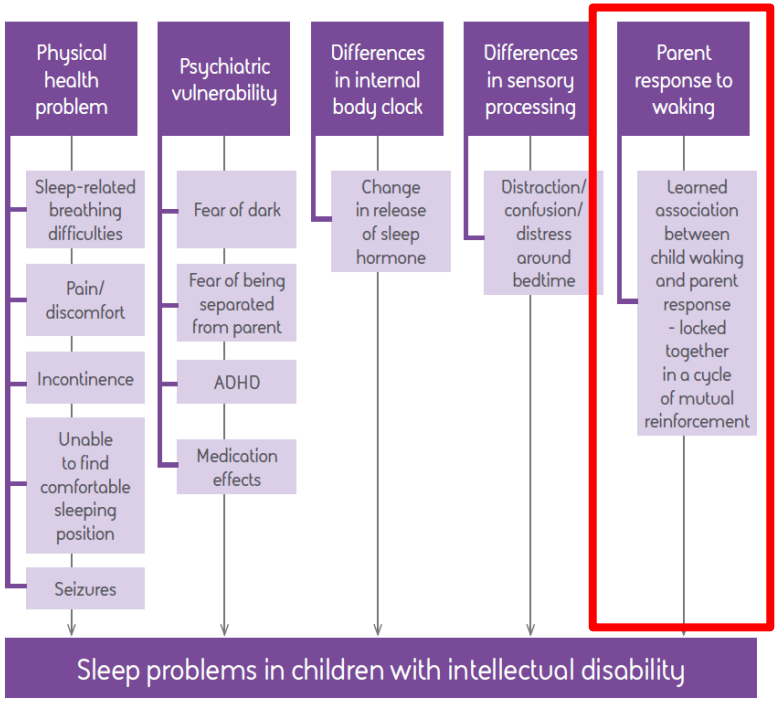
Take home messages so far …

- Sleep problems are prevalent in children and adults with TSC
- Sleep problems are unlikely to occur in isolation – affect other aspects of mood, attention, behaviour, and well-being
- Poor sleep in and of itself is a TAND behaviour that affects quality of life

Take home messages so far …

- Sleep problems are prevalent in children and adults with TSC
- Sleep problems are unlikely to occur in isolation – affect other aspects of mood, attention, behaviour, and well-being
- **Poor sleep in and of itself is a TAND behaviour that affects quality of life**

POOR SLEEP CAN BE BEHAVIOURAL

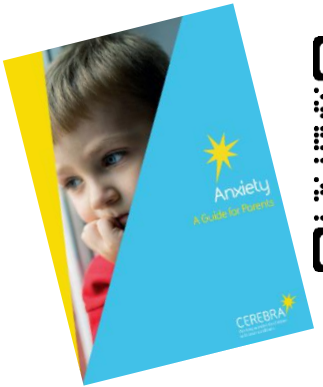


In some cases, poor sleep in TSC may be behaviourally reinforced

- Settling problems
- Struggling to return to sleep

SLEEP HYGIENE

1. **Keeping a regular schedule (consistent, predictable, naps)**
2. Teaching your child to fall asleep alone in their own bed
3. Encourage daytime activities that promote a better sleep/wake schedule (snacks, caffeine, exercise)
4. Providing a comfortable sleep setting (dark, quiet, dimly-light, cool, black-out blinds)
5. Establishing regular bedtime habits (consistent bedtime, bath before bed, quiet reading)



Agar, Trickett, Oliver, & Richards (2017). Sleep: A guide for parents.

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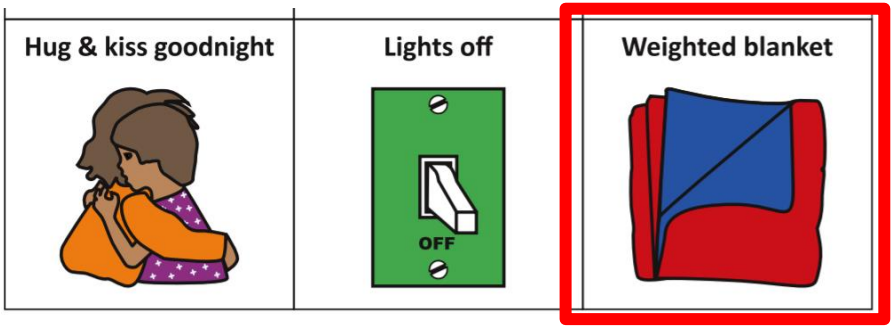

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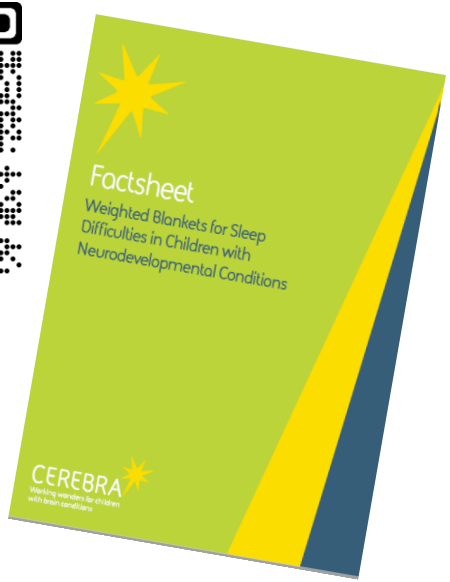
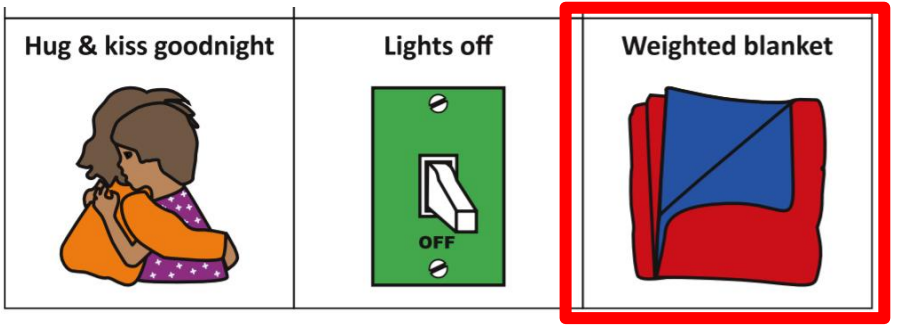
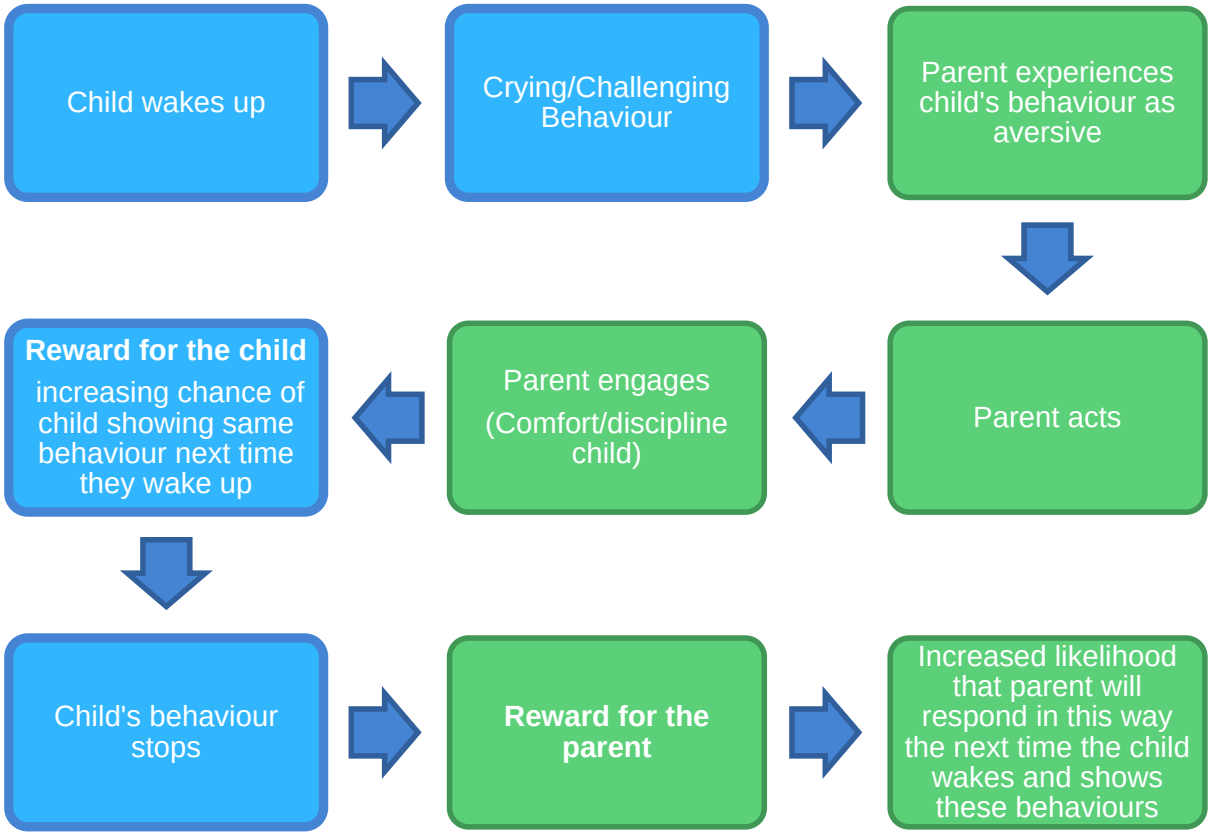


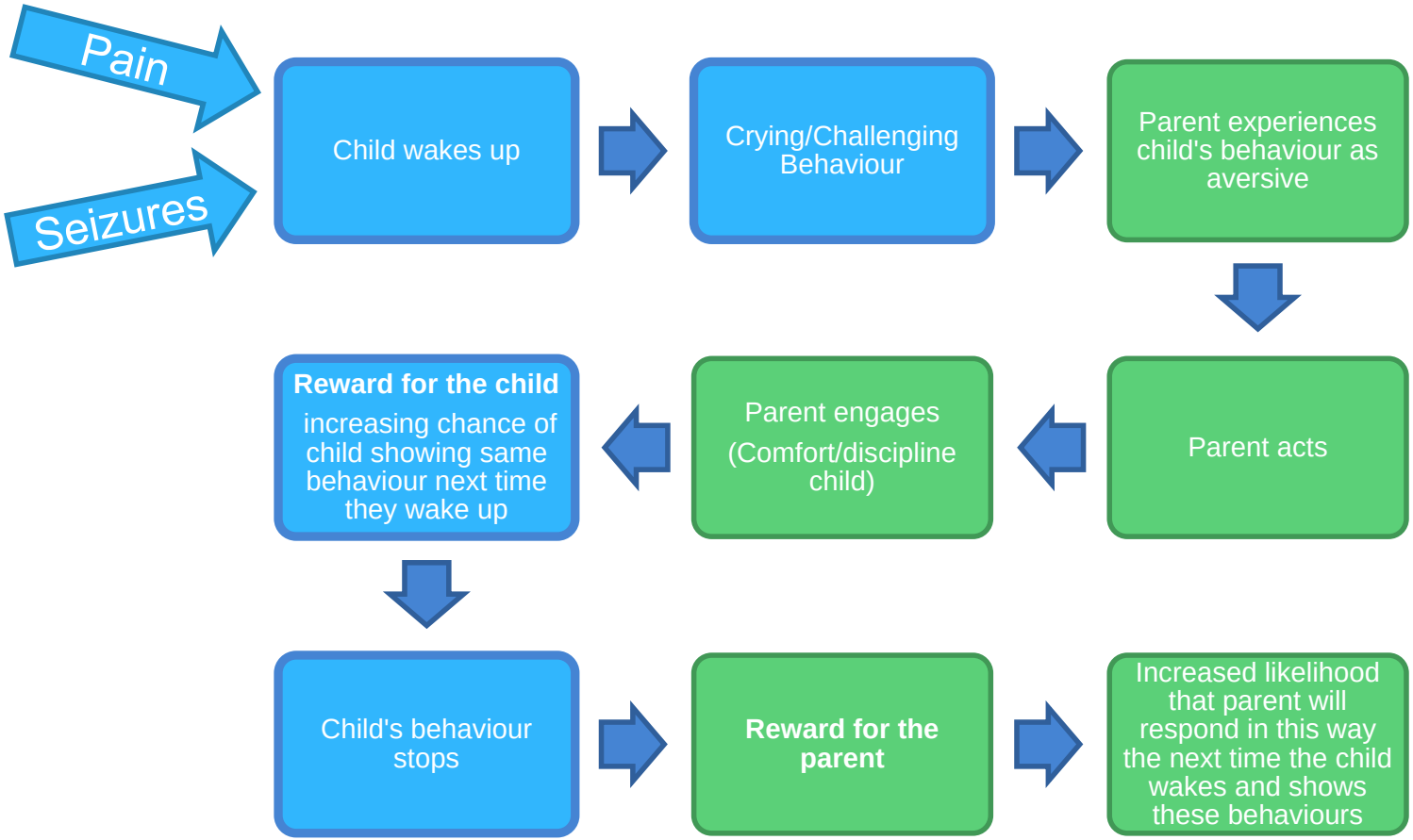


Sutherland, Agar, & Richards (2021). Weighted blankets for sleep difficulties in children with neurodevelopmental conditions

BEHAVIOURAL MODEL OF INSOMNIA



BUT REASONS FOR WAKING MAY BE TSC-SPECIFIC …



Take home messages so far …

- Poor sleep profile in TSC may be behavioural if maintained over time
- Co-occurring factors in TSC are important and may underlie poor sleep (e.g. pain, medication, seizures)
- Poor sleep can affect others aspects of behaviour
- Much of what we know about sleep in TSC is based on subjective measures (e.g. questionnaires)

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- Co-occurring factors in TSC are important and may underlie poor sleep (e.g. pain, medication, seizures)
- Poor sleep can affect others aspects of behaviour
- **Much of what we know about sleep in TSC is based on subjective measures (e.g. questionnaires)**

OBJECTIVE MEASURES OF SLEEP

Actigraphy	Watch-like device placed on wrist or ankle that detects movement as a proxy measure for sleep and wakefulness
Polysomnography	Electrodes placed on scalp and face throughout sleep duration
Videosomnography	Time-lapse methods used to record and score sleep behaviours

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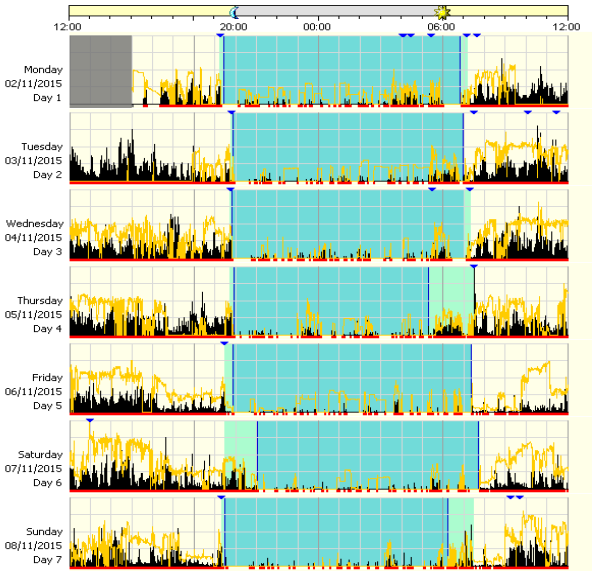
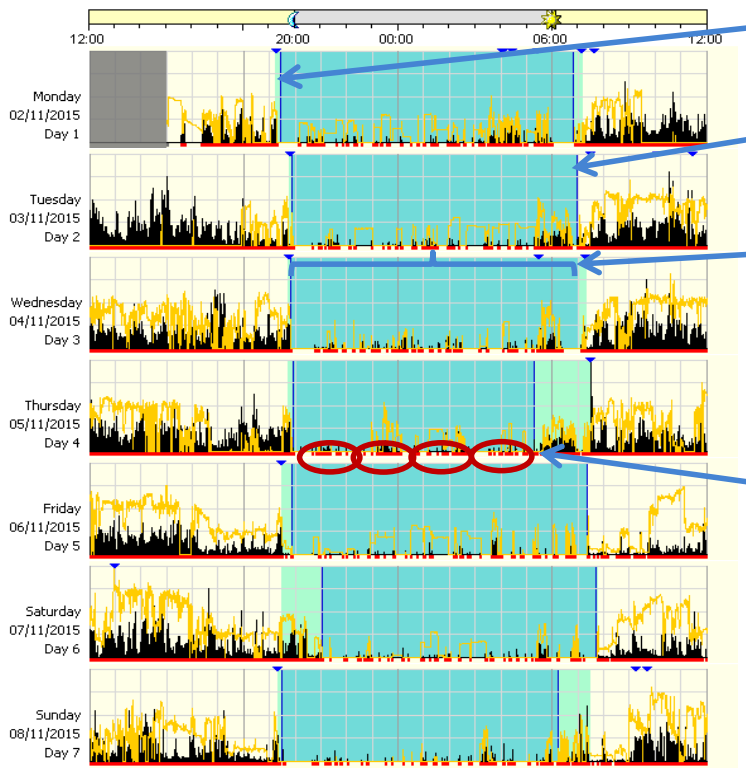


ACTIGRAPHY



Bed Time

Get Up Time

Total Sleep Time

Wake After Sleep Onset (WASO)

Time asleep

Time awake

Activity

External light

Falling asleep or snoozing

Event marker (caregiver)

ACTIGRAPHY STUDY IN TSC

Dr Caroline Richards | Prof. Chris Oliver | Prof. Petrus de Vries | Dr Stacey Bissell | Dr Lucy Wilde | Dr Cathy Hill | Dr Andrew Bagshaw

eSNORE

The Baily Thomas Charitable Fund

Exploring Sleep in Neurodevelopmental disorders through Online and Remote Evaluation (eSNORE)

- A **direct study of sleep** in children living in the UK **aged 4-15 years with TSC**.
- Monitoring children's daytime and night-time activity during a **ten day assessment period**.
- Recruited an age-matched typically developing group of children – BOTH GROUPS WEARING AN ACTIWATCH.

ACTIGRAPHY STUDY IN TSC

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eSNORE

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Exploring Sleep in Neurodevelopmental disorders through Online and Remote Evaluation (eSNORE)

Profile of poor sleep in TSC (a TAND behaviour)

How poor sleep may underlie other behaviours we see in TSC (association with TAND behaviours)

eSNORE research update for caregivers and professionals

09:30am – 1:00pm UK
28th September 2021

Richards Lab Birmingham

The Cerebra Network for Neurodevelopmental Disorders

The Baily Thomas Charitable Fund

University of Birmingham

FREE ONLNE RESEARCH EVENT

We are welcoming parents and caregivers of children with TSC, TSC researchers and health professionals to our online eSNORE research event!

eSNORE

Invited guest speakers will present research across three themes. There will be time for questions within each session. The event will conclude with an interactive live Q&A session and discussion. Attendees are welcome to join the event for part of the day, a single session, or for the whole event.

TANDem
Empowering families through technology

The Exploring Sleep in Neurodevelopmental Disorders using Online and Remote Evaluation (eSNORE) project was the largest direct study of sleep in children with tuberous sclerosis complex to date. Children aged 4-15 years with TSC in the UK wore activity monitors (actiwatches) to directly measure the profile of sleep across ten days. Children's daytime behaviour was also assessed via telephone interviews, online surveys and a mobile app diary. More information about the eSNORE project is available at: https://www.cerebranetwork.com/e-snore

Sleep in genetic syndromes and clinical considerations
09:30am-10:15am UK

Speakers:
Dr Georgie Agar (University of Birmingham)
Dr Catherine Hill (University of Southampton)

TSC research findings from eSNORE and the Cerebra Network
10:30am-11:15am UK

Speakers:
Dr Caroline Richards (University of Birmingham)
Dr Stacey Bissell (University of Birmingham)

Sleep in the context of TAND and the TANDem project
11:30am-12:15pm UK

Speakers:
Prof Petrus de Vries (University of Cape Town)
Dr Stephanie Vanclooster (Vrije Universiteit Brussel)

Live Q&A
12:30pm-12:55pm UK

Interactive live Q&A session with speakers

To register for this free online research event and submit questions ahead of time for the live Q&A session, please scan the QR code or visit our website:

https://www.cerebranetwork.com/e-snore