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HOT TOPIC

Recommendations for Assessing and Managing Sleep Problems in Children with Neurodevelopmental Conditions

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Abstract

Purpose of Review This review draws upon the authors' practical experience of assessing sleep in children with neurodevelopmental conditions alongside empirical evidence of recommendations for clinicians and researchers to support assessment of sleep problems and strategies to promote healthy sleep in children with specific neurodevelopmental conditions. These include communication about sleep, mental health/behavioural considerations, pain, sensory profile, epilepsy, melatonin secretion profiles, sleep-disordered breathing and restless leg syndrome.

Recent Findings This review has a particular focus on children with autism spectrum disorder, attention-deficit and hyperactivity disorder, Down syndrome, Smith-Magenis syndrome, Angelman syndrome, William's syndrome and cerebral palsy.

Summary Sleep disturbance varies in severity between neurodevelopmental conditions and the need for individualised assessment is emphasised. The impact of children's poor sleep on parents is highlighted as a particular concern. A checklist of recommendations and example resources for clinicians to enquire about sleep in children with neurodevelopmental conditions has been included in a summary table.

Keywords Sleep · Autism spectrum disorder · Attention-deficit and hyperactivity disorder · Down syndrome · Cerebral palsy · Clinician recommendations

Introduction

This review provides an introduction to the types of sleep disturbance experienced by children with neurodevelopmental conditions and a checklist for assessment of sleep and possible co-occurring physiological or psychological symptoms (Table 1). It focuses on children with common neurodevelopmental conditions autism spectrum disorder, attention-deficit and hyperactivity disorder, Down syndrome, Smith-Magenis syndrome, Angelman syndrome, William's syndrome and cerebral palsy. Finally, we discuss recommendations to support families of children with neurodevelopmental conditions with a sleep problem, based on research evidence.

Profile of Sleep Disturbance Across Neurodevelopmental Conditions

It is well established that individuals with neurodevelopmental conditions associated with intellectual disability are at a greater risk of sleep disturbance and shorter duration and poorer sleep quality compared with typically developing individuals [1••, 2]. Types of sleep disturbances reported among children with neurodevelopmental conditions include insomnia; both difficulty getting to sleep and maintaining sleep [3]. Excessive daytime sleepiness and sleep disordered breathing also affect children with some neurodevelopmental conditions [3]. In this section we consider how cross-neurodevelopmental condition studies have informed our understanding of the profile of sleep problems for specific conditions. Relative to other genetic syndrome groups, sleep disordered breathing particularly affects individuals with CHARGE syndrome, Down syndrome, Hurler syndrome,

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Table 1 Recommendations for screening for sleep disorders in primary care for children with neurodevelopmental conditions

Recommendation	Example
Use of short screening tool during routine appointments	E.g. the BEARS tool to screen for bedtime problems, excessive daytime sleepiness, waking during the night, regularity of bedtimes and wake times, average sleep duration and snoring.
Assess sleep practices prior to recommending interventions to improve sleep practices	E.g. completing the Family Inventory of Sleep Habits, designed for using with children with ASD. Discuss any areas where practices could be improved.
Assess underlying physical/biological causes for sleep problems	in neurodevelopmental conditions indicating abnormalities in melatonin secretions, consider assessing and treating with exogenous evening melatonin, where possible. It is worth noting that salivary and plasma assessments of endogenous secretion require the admission to a clinical facility, as dim light needs to be maintained. This assessment is predominantly conducted for research purposes, rather than as routine clinical practice in the UK. Further research is required to establish home-based protocols to assess endogenous melatonin in children with neurodevelopmental conditions. Assessment to rule out SDB, epilepsy, pain or PLMD.
Signpost families to specialist support services for sleep in children with neurodevelopmental conditions	E.g. the Cerebra Sleep Service, which provides one-to-one telephone support; Sleep Right by Scope who provide six sessions of one-to-one support for children who live in certain areas of England.
Evaluate parent mental health	Consider asking the child's parent/carer about their/their child's mental health which may be adversely affected due to their child's poor sleep. Refer to appropriate support.

ASD autism spectrum disorder, *PLMD* periodic limb movement disorder, *SDB* sleep disordered breathing

Mucopolysaccharidosis Type II, Mucopolysaccharidosis Type IV, Prader-Willi syndrome and William's syndrome [1••]. Excessive daytime sleepiness disproportionally affects individuals with Smith-Magenis syndrome relative to other genetic syndrome groups [1••]. Several studies have compared the relative severity and profile of sleep problems across children with different neurodevelopmental conditions using a standardised questionnaire and sleep diary data [4–6]. These data indicate that autistic children may be at heightened risk of sleep initiation difficulties relative to children with Angelman syndrome [6] although no between group differences were found in a study with a small sample of children with a genetic syndrome, to include Angelman syndrome [5••]. These findings also indicate that children with sensory processing disorders, cerebral palsy and children with genetic syndromes such as Smith-Magenis syndrome are at most risk of daytime sleepiness [5••]. Increased night waking is found for children with sensory processing disorders and when quantifying the severity of sleep problems, children with Smith-Magenis syndrome had the highest prevalence of severe night waking and waking before 5a.m. compared with children in other neurodevelopmental condition (NC) groups, including children with ASD [7]. Whilst infants and toddlers with Down syndrome, fragile X syndrome and William's syndrome do have poorer sleep quality and duration than typically developing children based on parent-report, comparisons across the three neurodevelopmental conditions reveal no differences in sleep quality and duration [4]. However, whilst at ages 6–12 years, there was no significant difference in actual sleep time when measured using actigraphy; sleep efficiency was lower in children with Down syndrome compared to children with William's syndrome due to extended night waking, whilst children with William's syndrome had longer sleep onset latency [8]. The extant literature evidences that children with NC's shorter sleep duration is due to either a longer sleep onset latency, night waking or a combination of both problems. By focusing interventions on either supporting children to fall asleep or stay asleep, targeting one or both of these problems would support a transdiagnostic approach to intervention development for sleep in individuals with NC.

Of note is that inversion of the circadian rhythm is commonly experienced in SMS [9], so that endogenous melatonin peaks during the daytime rather than at night, although inter-individual variation is reported [10]. Abnormalities in endogenous melatonin secretion are also reported for individuals with Angelman syndrome, with lower levels [11] and later timing of melatonin offset [12]. Individuals with William's syndrome and individuals with ASD have significantly lower nocturnal melatonin levels than typically developing individuals [9, 13]. There is evidence of delayed onset of melatonin secretion in individuals with ADHD compared with typically developing individuals [13]. For individuals with fragile X syndrome the minimum level of melatonin secreted during the daytime and the maximum volume secreted during the night was higher in boys with

fragile X syndrome compared with typically developing boys [14]. Taken together, these findings suggest that assessing the profile of endogenous melatonin secretion could be a useful part of a sleep assessment in children with ASD, Smith-Magenis syndrome, Angelman syndrome, fragile X syndrome or William's syndrome where divergent melatonin secretion profiles compared with typically developing children are reported.

Cerebral palsy (CP) is associated with significant sleep impairment, particularly demonstrating problems with initiating and maintaining sleep as well as sleep disordered breathing and subsequent daytime sleepiness [15, 16]. Compared with typically developing children, children with CP experience more sleep difficulties and at an earlier stage in their lifetime, and sleep impairment is significantly associated with the severity of CP [17]. Whilst sleep in children with CP is associated with co-occurring factors common amongst children with other NCs such as epilepsy, gastro-oesophageal reflux, mental health and behavioural difficulties, factors specific to CP such as upper airway obstruction, limited movement or muscle spasticity and visual impairment are also associated with sleep problems in this population (see [18] for a comprehensive review).

Sleep Assessment in Children with Neurodevelopmental Conditions

Sleep disturbances can be categorised into physiologically-based sleep problems, such as obstructive sleep apnoea, or behavioural sleep problems, such as behavioural insomnia. The International Classification of Sleep Disorders, third edition (ICSD-3) [19] categorises sleep disorders into seven categories: insomnia disorders, sleep-related breathing disorders, central disorders of hypersomnolence, circadian rhythm sleep-wake disorders, sleep-related movement disorders, parasomnias and other sleep disorders [19]. Different assessment methods are required for different sleep disorders.

The accurate assessment of sleep disturbance in children with neurodevelopmental conditions is critical in identifying correct treatment options. Sleep problems in paediatric populations are assessed with a combination of objective and subjective measures.

Questionnaires

For insomnia and parasomnias, screening may be carried out through parental questionnaires such as the Children's Sleep Habits Questionnaire, Pediatric Sleep Questionnaire [20, 21] and the BEARS screening tool [22]; however, self-reported sleep assessments, where appropriate, may also be used such as the Children's Report of Sleep Patterns [23]. The Simonds and Parraga Sleep Questionnaire [24] has been modified and used in children with autism and in those with intellectual disability (ID) [25, 26].

Subjective sleep assessments should include information broadly categorised as follows: settling to sleep, waking during the night, breathing difficulties during sleep, excessive or unusual movements during sleep, waking in the morning and tiredness levels during the day [27]. It is worth noting that the widely used Pediatric Sleep Questionnaire [20] which screens for sleep disordered breathing includes questions about behaviour; in children with neurodevelopmental conditions, hyperactive behaviour is more common [28], and therefore these children may obtain a higher score on this questionnaire for reasons unrelated to sleep disordered breathing. For children with neurodevelopmental conditions, self-assessment is not always possible, and parents/caregivers are often relied on as the child's ability to self-report may be hindered by intellectual disability and/or communication problems [27]. In particular, parents' reports of sleep are limited by (1) awareness of sleep quality, as parents may overestimate sleep duration and underestimate night waking duration [29–31] and (2) questionnaires only provide global information about sleep quality over a period such as a month, which does not account for night to night variation.

Actigraphy

Actigraphy allows the continuous assessment of sleep-wake monitoring. Sleep scheduling and therefore circadian rhythm and sleep quality can be assessed using actigraphy. Crucially, night to night variability in sleep duration, bedtimes and sleep quality can be assessed using actigraphy. An under-researched area is the role of variability in sleep and daytime functioning, as research from community samples has identified an association between greater sleep variability and poorer behaviour [32]. Actigraphy monitors are small, portable devices that are usually worn on the child's wrist, waist or ankle. These monitors are advantageous over polysomnography in that they are convenient, non-invasive and can provide information about a child's sleep-wake cycle over an extended period in their natural environment; however, they are limited in that they cannot provide information regarding sleep architecture or breathing. Sleep diaries should always accompany the use of actigraphy to help reduce artefacts related to device removal, periods of inactivity and externally induced movements [33]. An actigraphy cleaning protocol has been developed to clean actigraphy data using a combination of sleep diary and event marker data in children with neurodevelopmental conditions (See Appendix 1 in Agar et al. [34]). Through including both event markers and sleep diary data in the assessment, it increases the opportunities for parents to report on bedtime and wake time, which are needed for accurate actigraphy

cleaning. Actigraphy has been validated in children with autism [35] and shows a good level of agreement with PSG in children with ADHD [36] and Down syndrome [37]. However, caution should be taken when using the measure in a child's natural environment as validity research is typically carried out under highly controlled settings within a laboratory. Further guidance to carrying out actigraphy in children with neurodevelopmental conditions is provided by Fawkes and colleagues [38]. Actigraphy assessment of sleep has been conducted successfully with children with severe intellectual disability, through placement of the actigraph on the child's ankle [7] and in children with Smith-Magenis syndrome, who have a heightened risk of self-injurious behaviour [39]. Future work is needed to validate actigraphy within this population in home-based settings, in particular assessing whether ankle placement in children with severe intellectual disabilities and motor disorders, such as children with Angelman syndrome, has sufficient concurrent validity relative to polysomnography.

Polysomnography

Polysomnography (PSG) is the gold-standard objective method of measuring sleep disordered breathing. In addition to sleep duration and quality, it yields detailed information about the sleep architecture of the patient and is used as a diagnostic tool for sleep disorders such as obstructive sleep apnoea (OSA). PSG involves securing electrodes to a child's head, face, chest and legs, as well as monitoring their heart rate, respiratory effort, airflow, oxygen and carbon dioxide levels and is typically carried out in a sleep laboratory [40]. PSG can also be carried out in the home environment using ambulatory systems and this method is advantageous due to the procedure being more convenient for the participant. By sleeping in a familiar and comfortable environment and being able to adhere to a typical bedtime routine, anxiety around the procedure may be decreased. Home PSG studies may be more advantageous for children with complex needs due to increased prevalence of sensory difficulties within this population [41] and are accepted in children with ADHD and autism, but researchers, sleep physiologists or technicians should be prepared for equipment failures when conducting unattended home sleep studies [42]. Despite being considered the gold standard of sleep measurement, PSG is limited by being time-consuming for both participants and researchers as well as costly to administer. With reference to alternative options to assess sleep-disordered breathing, in children with Down syndrome, oximetry alone can sensitively detect most children at risk of clinically significant obstructive sleep apnoea [43] and could halve the number of children needing to undergo PSG studies. If an oximetry result does not fit the clinical picture of sleep-disordered breathing, cardio-respiratory studies are often used in practice to further investigations (for guidance and best practice see [44] for a comprehensive review).

Compliance with objective sleep assessments in children with neurodevelopmental conditions can vary depending on the level of ability a child possesses to understand and accept the procedure [27]. This may be further impacted if the child experiences co-occurring sensory processing disorder which is prevalent in children with neurodevelopmental conditions [45]. This does not mean that these assessments cannot be carried out, but that special considerations are required such as pre-appointment screenings to assess the child's medical background, level of communication and behavioural profile, to include hyperactivity and behaviour that challenges, before the procedure [46]. Children can also be given a 'dummy' actigraph before a sleep assessment, such as a fitbit device strap which they can wear for increasing long periods to acclimatise to wearing an actigraph for the duration of the sleep assessment.

To demonstrate, PSG and actigraphy have been carried out in children with ADHD [47, 48], autism [26, 49], Down syndrome [37, 43], and Angelman Syndrome [7, 50]. Paasch and colleagues devised a toolkit for carrying out PSG with children with neurodevelopmental conditions that they recommend consulting when carrying out sleep assessments within this population [46].

Supporting Parents with Home-Based Assessments

A careful approach must be taken when investigating sleep disturbance in children with neurodevelopmental conditions. It is important to note that parents of children with developmental delay may fail to recognise sleep problems when they occur and thus do not seek treatment [51]. Therefore, an important first step is for all developmental assessments to include screening for sleep disturbance. The initial screening should involve parental and self-reported measures, where appropriate, with objective methods being employed with special considerations where a more detailed assessment is indicated. Education targeted at parents regarding atypical sleep disturbance is needed to help empower caregivers during their child's assessment. It is recommended that parents are advised on the benefits of monitoring their child's sleep closely during the assessment period, and the disadvantages of completing sleep diaries retrospectively.

Sleep disturbance and related symptoms have been a growing area of interest during the COVID-19 pandemic [52]. Careful consideration must be given to ways of carrying out sleep assessments remotely. Most sleep research carried out in light of the COVID pandemic utilised online questionnaire methods to investigate the impact on mental health and other factors [53]. Actigraphy remains a viable objective option as devices can be cleaned between uses and sent out via post so that families do not require contact

with the researcher. We recommend using devices with event markers and providing specific instructions regarding device placement and completion of sleep diaries when using actigraphy. The use of parent-training videos instead of face-to-face visits with researchers could facilitate this and have been successfully used to collect data from typically developing children [7, 39].

Checklist for Clinicians

Families of children with neurodevelopmental conditions may seek help from their family doctor for support with their child's sleep. As screening for snoring is only implemented for a minority of children [54] combined with the limited sleep education given to medical students; only 25% of medical schools covered paediatric sleep [55], a checklist to support clinicians during consultations is required. A review identified poor knowledge as being the greatest barrier to implementing screening for sleep problems [56] and risk of diagnostic overshadowing, where other medical and mental health conditions take precedence; there is a need for additional tools to support clinicians to screen for sleep in children with neurodevelopmental conditions. In Table 1 we outline some recommendations for screening for sleep disorders in primary care.

Interventions for Sleep in Children with Neurodevelopmental Conditions

With regard to sleep disordered breathing in children with neurodevelopmental conditions, several diagnosis-specific recommendations for assessment and treatment of sleep disordered breathing in neurodevelopmental conditions are reported [57].

With respect to intervention for insomnia in children with neurodevelopmental disorders, clear identification of the types of sleep problems that affect the child and family requires a comprehensive evaluation, ideally using subjective and objective methods in combination. In the context of caring for a child with a neurodevelopmental condition, a parent's relative priority for treating sleep disturbance is likely to depend on other medical symptoms or behavioural problems that the child is experiencing. As the first line intervention strategy for insomnia problems involves a parent-implemented sleep hygiene/behavioural intervention [58], parents should be consulted on their capacity to use behavioural strategies to support their child's sleep and the most appropriate timing of this intervention for the family [59]. Parents indicated that support for implementing behavioural strategies was the most frequently endorsed priority to support sleep in children with Angelman syndrome (27%) [60]. In this section, we focus our review on behavioural interventions and sensory sleep aids, as pharmacological interventions for insomnia in children with neurodevelopmental conditions has been reviewed elsewhere [61].

Behavioural Interventions

Should insomnia, either due to sleep initiation or maintenance difficulties, be identified as the target for intervention, strategies used among typically developing children appear to be effective among children with neurodevelopmental conditions, including autistic children and children with ADHD [62]. It is suggested that behavioural strategies such as psychoeducation about sleep hygiene and behavioural techniques to reduce parental attention in response to extended sleep onset latency or night waking may be effective across neurodevelopmental conditions [62]. Sleep practitioners have reported that the following modifications to strategies may be helpful for families of children with neurodevelopmental conditions: accounting for children's severity of intellectual disability, building routines, supporting parents to adjust their expectations about change, modifying the child's sleeping environment, providing support for managing transition in routine, accommodating the child's sensory profile and using visual aids [63]. However, for children with a NC with co-occurring epilepsy, sensory processing difficulties, anxiety, challenging behaviour or other medical needs, the choice of behavioural strategy used should consider co-occurring physiological and mental health difficulties. Behavioural interventions can be categorised into antecedent-based and consequence-based sleep interventions. Antecedent-based behavioural sleep interventions involve changing the child's sleep/wake schedule whereas a consequence-based sleep intervention focuses on eliminating or withdrawing reinforcement and using rewards for 'good' sleep behaviours. Examples of antecedent-based interventions that have shown to be effective in children with neurodevelopmental conditions are as follows: faded bedtime in which the child's bedtime is consistently moved earlier until an appropriate bedtime is reached [64], stimulus substitution as part of fading parental response such as providing the child with a soft toy [65] and visual supports such as a Gro-Clock™ can provide children with a visual representation of when they should be sleeping versus when they can be awake [66]. In a review of interventions for sleep in children with rare genetic syndromes, to include SMS, Angelman syndrome and William's syndrome, the interventions involved multiple components, so it is challenging to isolate the most effective strategy. In a review of randomised control trials of behavioural interventions to support sleep in children with neurological disorders or neurodevelopmental conditions, using actigraphy data, only small to moderate effects of the intervention were found for total sleep time

(extra 24 min from baseline to post-intervention) sleep onset latency (8 min faster from baseline to post-intervention) and there were no improvements in total night waking duration. In contrast using self or parent reported night waking, a moderate improvement was found from baseline to post-intervention [67]. The only randomised control trial of a behavioural intervention for children with rare genetic syndromes, found significant improvement on parent rated sleep problems after an intervention comprised of sleep-hygiene, education on the role of reinforcement in the maintenance of sleep problems and modified extinction both when information was delivered by a therapist in one condition and via a booklet in another condition relative to a control group [68]. However, as identified from Philips et al.'s (2020) review, parent-reported sleep outcomes show larger effects than objective outcomes. Nevertheless, these findings, combined with parents indicating that they received sufficient support during a feasibility study of a telehealth intervention, which included children with ASD and ADHD [69] indicate that intensive clinician support to implement behavioural strategies to improve sleep may not be necessary for all families. Although when parents reported on their experience of a therapist-led sleep intervention they stated that the individualisation of the intervention and support received from therapist was highly valuable to enable them to be persistent with applying strategies and for accountability [70]. The takeaway message from these studies is that clinicians should identify what types of support parents need to facilitate change in their child's sleep routine (e.g. increased confidence to manage problems, education about strategies and support with adapting strategy to child's specific needs) to recommend the most appropriate format of intervention delivery, where a choice of intervention programmes is available.

Sensory Sleep Aids

Children with sensory processing difficulties, which often co-occur with neurodevelopmental conditions, may respond well to using sensory sleep aids, such as weighted blankets, compression clothing or sheets, or firm massage at bedtime, although evidence is lacking and mixed.

Both hyper- and hypo-sensitivity to sensory features are a diagnostic criterion for autism [71]; thus, any use of sensory sleep aids should be individualised for the child. Evidence for efficacy is mixed, for example, in a clinical trial involving 67 children with ASD, weighted blankets were preferred compared to normal-weight blankets, and well tolerated by children with ASD and their parents, but with no evidence that they actually improve sleep [72]. Interventions using white noise to mask external noise or vocalisations have been well tolerated by parents and children with ASD, and shown some improvements in sleep onset delay, although it is not clear whether improvement can be attributed to the white noise or other strands of the interventions [73]. A randomised crossover trial of the Sound-to-Sleep Mattress, which plays synchronised tunes and vibrations, showed improved sleep duration and efficiency and was tolerated well but did not significantly reduce sleep onset latency in 45 children with ASD [74].

Parents of 1002 children with ASD delivered an internet mediated sensory enrichment intervention through short daily activities lasting around 30 min per day for up to 7 months [75]. Children's sleep improved over the course of the intervention suggesting that an increased daytime sensory diet may improve night-time sleep. Similarly, multiple studies involving an increase in daytime exercise or sensory experiences, such as aerobic exercise [76] and yoga [77] have shown an improvement in night time sleep for children with ASD. Whilst these interventions show good evidence for efficacy, the load for parents is great, thus reducing consistent adherence to the programmes.

Bed tents, which reduce external stimulation may be particularly helpful for some children with autism as they create a contained safe space for sleeping which excludes external stimulation, yet scientific support is lacking. In summary, for children with ASD, where sensory issues are common, sensory sleep aids may show some efficacy, in isolation or combination, but should be tailored to the child's particular needs. Examples of specific considerations for different NC groups are given in Table 2. Please note that these considerations may apply to individual children beyond the NC group specified, and the communication, behavioural, medical and sensory needs of children should be assessed on an individualised basis. As well as addressing the families' needs, it is suggested that greater personalisation of sleep strategies may increase motivation to implement the intervention [78]. A selection of sleep hygiene strategies suitable for children with NC was co-developed with parents and sleep practitioners following an evidence-based scoping review [78]. Stakeholders identified the need for sleep disturbances in children with NC to be legitimised, to include greater prioritisation of support for sleep in children with NC by policymakers [78].

Recommended Strategies for Children with Neurodevelopmental Conditions (See Table 2)

Communicating Expectations About Sleep with the Child

Children may struggle with change in routine. The use of visual timetables so that the child knows what to expect at bedtime should be considered. Clinicians should also consider graduated extinction rather than unmodified extinction. Graduated extinction refers to a parent ignoring the child's signalling behaviours for attention for a set period of time before

Table 2 Recommendations for clinicians to support sleep in children with neurodevelopmental conditions

Considerations	ASD	ADHD	Down syndrome (DS)	Smith-Magenis syndrome (SMS)	Angelman syndrome (AS)	William's syndrome	Cerebral palsy (CP)
Communicating expectations about sleep with the child	x	x	x	x	x	x	x
Behavioural/mental health considerations	x	x	x	x	x	x	x
Painful health conditions	x			x	x		x
Epilepsy	x		x	x	x	x	x
Sensory profile	x	x		x			
Sleep-disordered breathing			x				x
Restless leg syndrome/periodic limb movement disorder (PLMD)	x	x	x	x	x	x	x

checking on the child. Unmodified extinction refers to ignoring behaviours completely so that the child learns to self-soothe [62]. Parents should provide consistency in bedtime routine.

For children who get out of bed multiple times when trying to settle to sleep parents should consider 'checking in' whereby the parent goes to check on the child frequently, allowing the child to become used to staying in bed. The frequency in which parents check in on the child decreases as the child becomes more used with staying in bed. Set clear expectations for child during night waking such as staying in bed/in their room. For children with severe receptive communication difficulties, such as children with Angelman syndrome, consider extinction with parental presence during interactions after the child has been put to bed.

Behavioural/Mental Health Considerations

Consider providing unstimulating toys for the child to use during extended periods of waking. For children who are able to communicate verbally or via augmented or alternative communication devices, ask children to name anything that they are worried about before going to sleep. The adult then writes down that worry on some paper and put it in a box. Children can then feel that they have offloaded their worry, so they do not need to think about it and become stimulated whilst trying to fall asleep. The role of mental health in maintaining sleep problems should be particularly considered in individuals with ASD, as 40% of these children and adolescents have an anxiety disorder [68]. Children with ADHD may also experience higher rates of anxiety and/or depressive symptoms than typically-developing children [69]. Children with William's syndrome are at very high risk of experiencing anxiety, as they have a fourfold risk of experiencing anxiety than children with other neurodevelopmental conditions [79].

Children with SMS may engage in self-injurious behaviour upon waking during the night. Children are often awake for extended periods and may try to leave their room and put themselves at risk without adult supervision. The use of safety sleeper beds and the provision of unstimulating toys for the child to use during extended periods of waking should be considered. Professionals should note that keeping children with SMS safe at night was the primary priority for parents [80].

Painful Health Conditions

Ensure a pain assessment such as the FLACC checklist is completed. Behavioural indicators of pain prior to sleep onset are observed in children with SMS and prior to and after night waking in children with AS [81]. Musculoskeletal pain, neuromuscular pain and gastrointestinal pain is associated with CP [82]. These painful conditions may impact on sleep in children with CP, as children and young people with CP with problematic pain indicated this interfered with their sleep [83].

Epilepsy

For any children who experience epilepsy, including children with Angelman syndrome who are at high risk for experiencing seizures, consider the use of technology to detect seizures at night [84].

Sensory Profile

Consider removing toys that provide excessive stimulation from the bedroom and only associate the bedroom with sleep. Ensure noise and light levels are minimised to limit arousal in children with hyperarousal [74]. Children's hypersensitivity to touch is associated with sleep disturbances. Parents may want to consider avoiding touch during the child's bedtime routine if their sensory profile indicates touch hypersensitivity [75]. Increased physical or sensory activities during the day may promote night-time sleep, as some children with ASD (4/10) who received a weekly individualised swimming intervention for 8 weeks based on their sensory and communication profile showed improved sleep based on a parent-completed questionnaire [85].

Melatonin Profile

Children with neurodevelopmental conditions can have lower, delayed or supressed levels of melatonin than typically developing children (see the "Profile of Sleep Disturbance Across Neurodevelopmental Conditions" section). Treatment with melatonin reduces time taken to fall asleep, though there is no evidence for improved sleep maintenance [86].

Sleep-Disordered Breathing

Sleep-disordered breathing may be assessed by ear, nose and throat assessment with indication for adenotonsillectomy and weight loss to treat OSA. Continuous positive airway pressure (CPAP) may be used for residual OSA. OSA is common in DS and should be assessed before age four and regularly reviewed [87]. CPAP mask tolerance is mixed.

Restless Leg Syndrome/Periodic Limb Movement Disorder (PLMD)

This may be associated with low ferritin levels. May be secondary to iron deficiency due to narrow food preferences in individuals with ASD. In William's syndrome, treatment with clonazepam has shown efficacy [88]. Where serum ferritin levels are less than 50 µg/L, treatment with iron sulphate is effective in reducing the period limb movement index in children, to include children with ADHD [89].

Impact on Parents

Parents of children with NC often have multiple responsibilities, not only as a parent, but as a carer providing physical and emotional care beyond what would be required for typically developing children. Parents of children with complex care needs described themselves being a health care provider, case manager, student, teacher, detective, guard and advocate for their child [90]. Parents of children with an intellectual disability experience both poorer sleep quality and higher parenting stress than parents of typically developing children [91]. When controlling for gender and body mass index, parental stress, which was higher in parents of children with a NC compared with parents of children without an NC, explained 16% of the variance in parents of children with NC's sleep quality [91]. A review identified parents of children with NC to have sleep duration of 4.8 to 6.9 h, which is below the minimum recommendation for healthy adults, and poorer sleep quality than parents of typically developing children [92]. Of note is that parents of children with Angelman syndrome, who provide a high level of care for their children with severe to profound level of intellectual disability, stated that the most stressful impact of their child's sleep was upon their own ability to function during the day (endorsed by 42% of parents) [60]. Whilst there is a lack of published evidence on the of the family's environment, such as financial pressure, single-parent households, overcrowded or inadequate housing on sleep with children with NCs, there is evidence from the typical population that families with great financial hardship, combined with caregiver stress is associated with greater variation of sleep duration from night to night [93]. As families of children with intellectual disabilities are likely to have a low household income [94] and experience stress [95], it is possible that these factors could exacerbate sleep problems in the NC population. Taken together, these findings indicate that the impact of children's sleep on the wider family, in particular parents who provide extensive care for children with neurodevelopmental conditions should not be underestimated and should be evaluated alongside the child's sleep when conducting sleep assessments (Table 1).

Conclusions

Sleep problems in children with neurodevelopmental conditions are varied and are often associated with increased syndrome severity, cognitive and behavioural difficulties, and poorer mental health, as well as stress for the family.

Careful considerations should be taken when assessing sleep in children with neurodevelopmental conditions (Fig. 1). Researchers and clinicians should consider using well-validated questionnaires alongside objective measures such as actigraphy and PSG as parent report does not accurately capture night waking. Education targeted at parents regarding atypical sleep disturbance and information regarding actigraphy device placement and completion of sleep diaries is needed to help empower caregivers during their child's assessment.

All children with NC are at increased risk of difficulties falling asleep and staying asleep. For certain groups, such as children with Smith-Magenis syndrome there is a biological aetiology for sleep disturbance due to inversion or suppression of endogenous melatonin. Clinicians should assess current sleep hygiene practices before considering the recommendation to undertake a sleep hygiene psycho-intervention. Clinicians should also consider children's behavioural, mental health, communication skills, medical conditions, and sensory profile to tailor behavioural strategies. Finally, clinicians should consider parents/carers capacity to implement parent-led behavioural interventions, accounting for parent mental health, family dynamics and caring arrangements.

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Practice Points

- The severity of sleep disturbance can differ between NCs, evidenced by daytime sleepiness and night waking disproportionally affecting children with Smith-Magenis syndrome.
- Shortened duration of nocturnal sleep in children with NCs is due to night waking, difficulty getting to sleep or a combination of both problems.
- As sensory, behavioural and communication needs do overlap between neurodevelopmental conditions, transdiagnostic modules on sleep strategies adapted with common considerations across neurodevelopmental conditions could be developed.

Research Agenda

- Future research is needed to validate actigraphy against gold standard polysomnography in children with neurodevelopmental conditions.
- Further research on the melatonin secretion profile of children with different neurodevelopmental conditions is needed.
- Sensory sleep aids are commonly marketed to aid sleep in children with NCs, however evidence of efficacy is lacking. Products should be control-trial tested where possible.
- Further research on cognitive, behavioural and health associates of sleep problems should be conducted in children with NCs.

Fig. 1 Practice point and research agenda

Data Availability Not applicable

Declarations

Ethical Approval Not applicable

Competing Interests The authors declare no competing interests.

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Papers of particular interest, published recently, have been highlighted as:
- • Of importance
- •• Of major importance

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