2014

# Insom

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## Pediatric Behavioural Insomnia in Children with Neurodevelopmental Disabilities – **Strategies to Improve Sleep**

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Sleep problems in children with neurodevelopmental disorders (NDDs) such as autism spectrum disorder and attention deficit/hyperactivity disorder are more common than in typically developing children. Many factors likely contribute to sleep problems in children with NDDs including family, environment, behavioural and neurobiological factors, as well as comorbid medical and psychiatric disorders, primary sleep and circadian rhythm disorders and medications. This issue of Insomnia Rounds discusses the evaluation of sleep problems in children with NDDs as well as therapeutic interventions. Our focus is on behavioural insomnia in children with NDDs; ie, those sleep problems that are behavioural in nature. A review of behavioural insomnia in typically developing children was featured in a previous issue.<sup>1</sup>

## What is the prevalence of sleep problems in children with neurodevelopmental disorders (NDDs)?

Sleep is essential for the healthy development of children; however, pediatric sleep problems are very common, affecting approximately 20%-30% of all children.<sup>2</sup> The prevalence is significantly higher in children with NDDs such as autism spectrum disorder (ASD) and attention deficit/hyperactivity disorder (ADHD) than in typically developing children.<sup>3-6</sup> It has been estimated to be 40%-95%,<sup>5,7-9</sup> depending on how sleep problems are defined and measured. Research shows that children with NDDs are reported by their parents to have the most difficulty with the following:7,8,10,11

- · Poor sleep routines
- · Bedtime resistance
- · Frustration and conflict at bedtime
- Sleep onset/settling issues
- · Night awakenings
- Irregular sleep-wake patterns
- · Early morning awakenings
- · Shortened sleep duration
- Daytime sleepiness

## What factors could contribute to sleep problems in children with NDDs?

Compared to parents of typically developing children, parents of children with NDDs tend to think of their children's sleep problems as more medically based than behavioural in nature.<sup>12</sup> For this reason, many parents may be less likely to seek help and pursue treatments, feeling that treatment may not be effective, and/or may seek medical rather than behavioural treatment. It is important to note that despite the high prevalence of sleep problems in children with NDDs, later bedtimes rather than intrinsic/physiological factors is the most common reason for reduced sleep duration.<sup>13</sup> However, based on empirical research,<sup>5,14,15</sup> many factors can contribute to sleep problems in children with NDDs (Figure 1).

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Montreal, QC

## Figure 1: Examples of factors contributing to sleep problems in children with neurodevelopmental disorders (NDDs)

## **Behavioural factors Child factors** Lack of structure and routine Temperament Bedtime/limit-setting issues Hypersensitivity to environmental stimuli Repetitive thoughts/behaviours Difficulty with self-regulation • Difficulties with the communicative/ Altered regulation or perception social aspect about sleep of stimuli Nighttime fears and nightmares – trouble communicating their concerns Comorbid neurological, medical, and psychiatric disorders **Family variables** Epilepsy Sleep hygiene practices Gastrointestinal disease (eg, reflux/constipation/ Household routines altered gastrointestinal motility) • Parental mental health • Mental health (eg, anxiety or depression) Family composition Eczema/atopy/allergies Family work and school schedules Recurrent infections Parenting styles and responses Primary enuresis or Parental expectations encopresis **SLEEP** PROBLEMS **Neurobiological factors Medication** Possible disruption of the neurotransmitter Medications for comorbid neurological, systems that promote sleep and establish a regular medical, and mental health disorders sleep-wake cycle: gamma aminobutyric acid, serotonin, and melatonin

## Primary sleep disorders

 Sleep disordered breathing (eg, obstructive sleep apnea, central sleep apnea, sleep-related hypoventilation, obesity hypoventilation)

- Parasomnias (eg, sleepwalking, night terrors, teeth grinding)
  - Non-rapid eye movement arousal disorders
  - (eg, night terrors, sleep walking, confusional arousals)
- Rapid eye movement-associated sleep abnormalities (eg, frequent nightmares)

Sleep-related movement disorders (eg, rhythmic movement disorder, restless legs syndrome,

periodic limb movements in sleep, periodic limb movement disorder)

Circadian rhythm disorders (eg, delayed or advanced

sleep-phase disorder or irregular sleep-wake rhythm)

# What is the impact of sleep problems on children with NDDs?

Sleep problems in children with NDDs can cause insufficient, fragmented, or nonrestorative sleep, which in turn can negatively affect daytime functioning and exacerbate or worsen the symptoms of the NDD. For example, reduced sleep can negatively affect attention, behaviour, and emotional regulation in typically developing children. Therefore, children with ADHD, who are characterized by difficulties with attention and behaviour, are more likely to experience and demonstrate an increase in their symptoms if they also have sleep problems.<sup>7,8</sup> Sleep problems in children with NDD are also associated with a negative impact on overall cognitive functioning and increased internalizing and emotional

troubles such as anxiety.<sup>16-23</sup> It is important to note that these are common associations between NDDs and sleep problems; however, there are no causal data.

# What are the key features to consider in the evaluation?

Although sleep problems are common in children with NDDs, they are often overlooked, or even misdiagnosed in the assessment, diagnosis, and treatment of these children. In addition to history and physical examination, primary care health professionals can evaluate sleep by asking parents to record a sleep diary for 7–14 days (for an example, see the first issue of *Insomnia Rounds*,<sup>24</sup> or refer to www.sleep-forkids.org/pdf/sleepdiary.pdf for child-friendly variations). The sleep diary should contain detailed information about bedtimes, waking time, sleep onset time, presence of night waking, returning to sleep, and daytime napping. Recording parental response to the child's sleep problems can also be very helpful. If the sleep problem is related to a medical issue (eg, obstructive sleep apnea, gastrointestinal reflux, seizures), further consultation is required.

Given the high prevalence of sleep problems in this population, it is recommended that all children with NDDs be screened. The Resources section at the end of this article lists some good screening tools. While no tools are specifically designed for children with NDDs, the BEARS is a 5-item screening tool that examines 5 major domains of children's sleep: Bedtime problems, Excessive daytime sleepiness, Awakenings during the night, Regularity of sleep/wake cycles, and Snoring.<sup>25</sup> For children with ASD, the Sleep Committee of the Autism Treatment Network (ATN) has published a practice pathway for the evaluation and management of insomnia (see Resources).<sup>26</sup>

## How should sleep problems in NDDs be treated? Behavioural

In a previous issue of *Insomnia Rounds*,<sup>1</sup> Weiss and Corkum highlighted some behavioural interventions for typically developing children with insomnia (see Resources). The basis of treatment for children with ASD and ADHD with sleep problems is the same as for typically developing children and includes parent education, sleep hygiene, and behaviour interventions. The ATN has published a brochure for parents of children with ASD and sleep problems on their website (www.autismspeaks.org), as well as a tool kit with specific strategies that parents can use. Please see the resources section below for the ATN brochure, and websites with resources for children with ADHD.

Tables 1 and 2 outline sleep intervention strategies for children with NDD, with a specific focus on children with ASD and ADHD. Table 2 summarizes the first of the 3 main strategies for achieving better sleep in children, parent sleep education, with some specific considerations for NDDs in general as well as ADHD and ASD specifically. Table 3 summarizes key sleep hygiene strategies for children with NDDs, including specific modifications or concerns for children with ADHD and ASD. Beyond sleep education, improving

## Table 1: Sleep education for parents of children with NDDs

- Parents should be aware of the negative impact of fragmented or reduced sleep on children's daytime functioning.
- Awareness of how sleep problems can impact their child can help to encourage families to stick to a consistent and regular sleep schedule. It may take some time for the whole family to grow accustomed to using a regular sleep schedule, but sticking with the schedule is key.
- Children with NDDs may find it easier to stick to a routine or schedule if there is a visual schedule for them to follow. For example, a checklist or series of pictures identifying all the things that need to be done before bed can be posted in the bedroom. Children with NDDs may require more time to get used to a routine.
- Parents of children with NDDs tend to believe that their children's sleep problems are more intrinsic, less modifiable, and less responsive to treatment compared with parents of typically developing children.<sup>35</sup> It is important to ensure that parents know that sleep problems can, in fact, be treated.
- Staying positive and making time for some parent-child quiet time at bedtime leads to more relaxed experience for everyone. Often children with NDDs have been working hard all day to manage themselves at school and at home, so quiet, positive time with a parent before bed can be especially rewarding and will lead to children feeling more positive about their whole day.
- Goals should be small and incremental. Little steps can help to improve sleep. Staying positive and supportive is also helpful. Encourage parents to be role models for good sleep health and hygiene.

sleep hygiene is often the first line of treatment for children with NDDs.<sup>27</sup>

Although we know that behavioural interventions are highly effective in treating typically developing children's sleep problems,<sup>28</sup> there has been very little published research on what behavioural strategies for sleep problems work best for children with NDDs.<sup>29</sup> A recent review of treatment strategies for complex behavioural insomnia in children with NDDs<sup>30</sup> endorsed the use of cognitive behaviour insomnia therapies as a first-line treatment for children with ASD, followed by supplements such as oral melatonin or other sedative/hypnotic medications should problems remain. Above all, the review emphasized that the foundation of behavioural insomnia therapy in NDDs is parents as agents for change of problematic sleep behaviours.

Several behaviourally based treatments have been found to be effective for children with NDD, including faded bedtime with response cost and positive reinforcement,<sup>29,31,32</sup> standard extinction,<sup>33</sup> and graduated extinction.<sup>10,34</sup> Importantly, behavioural interventions may need to be tailored to

General considerations	NDD-specific considerations
Adhering to bedtime routines, regardless of season, can help build consistency around the time of night children are ready for bed.	<ul> <li>Children with NDDs may require more time and a few more reminders than their typical peers to get through their routine. However, make sure that they do not have too much time, as distraction may take over and the routine may be delayed longer than necessary.</li> </ul>
	• Trial and error may be required to determine the best routine for an individual child.
	• Expect roadblocks or setbacks with illness, certain times of the year like time changes or holiday seasons, and vacations.
	<ul> <li>Although children with NDDs typically respond well to routines, they can sometimes become overly fixated on them and refuse to go to sleep unless routines are followed very specifically. Introducing a small amount of variation into the bedtime routine each night (eg, reading a different book or wearing different pajamas each night) can help to prevent this.<sup>36</sup></li> </ul>
<ul> <li>Healthy eating and physical activity during the day (and not too close to bedtime) are helpful to ensure a child will be ready for bed at night.</li> <li>Bedtime activities should be calming and relaxing, in order to prepare the child for sleep. Watching television and playing with electronic devices right before bed makes it more difficult to fall asleep and stay asleep.</li> <li>Calming activities include quiet baths, listening to stories/lullabies, and/or having a small snack.</li> </ul>	<ul> <li>Ensuring that children with NDDs have sufficient opportunities to exercise during the day is critical. Many children with ADHD enjoy sedentary activities such as videogames, so parents may have to work a little harder to ensure that their children get enough physical activity. Activity earlier in the day may help to promote sleep at night.</li> </ul>
	<ul> <li>As for all children, bedtime activities should be calming and simple. Activities that involve new or unexpected events,</li> </ul>
	<ul> <li>excessive noise, or vigorous exercise may be overstimulating.<sup>27</sup></li> <li>Heavy meals, temperature changes, and certain medications should be avoided at bedtime.<sup>27</sup></li> </ul>
The sleep environment (ie, the bedroom) should be set up to be as conducive to sleeping as possible, keeping in mind the sensitivities of the child. The presence of familiar toys/blankets and a comfortable bed can be helpful.	<ul> <li>Children with NDDs may be easily distracted and require visual reminders of the bedtime routine in their bedroom.</li> <li>Keep devices such as televisions, computers, and gaming equipment out of the bedroom.</li> <li>Children may have motor disabilities, sensory sensitivities, and hypersensitivity to environmental stimuli, all of which can influence how to arrange the bedroom.<sup>27</sup></li> </ul>

## Table 2: Sleep hygiene strategies for children with NDDs

a child's cognitive or developmental level, and NDD symptomatology should always be taken into account when designing and implementing interventions.<sup>29</sup> For children with NDDs, the use of simple behavioural strategies such as reward programs may be especially helpful for promoting desirable behaviours, decreasing unwanted behaviours, and helping children to follow routines; eg, parents might use a sticker chart to help motivate their child to follow bedtime routines.

## Pharmacological

Pharmacotherapy that may have a negative impact on sleep. Children with NDDs often take psychotropic medications for the management of symptoms related to behaviour or other challenges. It is important for healthcare professionals who work with these children to know that many psychotropic medications have been shown to affect sleep adversely. For example, children with ADHD who take stimulant medication have difficulty with sleep onset latency and sleep duration.<sup>37,38</sup> Therefore, children with ADHD who take stimulant medications may demonstrate increased sleep difficulties, particularly at bedtime.<sup>39,40</sup> It is important for parents of children with NDDs to consider this information, as they will need to weigh the benefits of medication on daytime symptoms versus the adverse effects on sleep. In particular, it is also important for healthcare professionals to consider the



## RESOURCES

## Websites

- Canadian Sleep Society http://www.canadiansleepsociety.ca
- National Sleep Foundation
   http://www.sleepforkids.org
- Dalhousie Child Clinical and School Psychology Research Lab http://betternightsbetterdays.ca

## Key articles and reviews

 Review of sleep hygiene practices in children with sleep problems and NDDs

Jan JE, Owens JA, Weiss MD, et al. Sleep hygiene for children with neurodevelopmental disabilities. *Pediatrics*. 2008;122(6):1343-1350.

Overview of sleep problems and ADHD

Corkum PV, Davidson F, MacPherson M. A framework for the assessment and treatment of sleep problems in children with attention-deficit/hyperactivity disorder. *Pediatr Clin North Am.* 2011;58(3):667-683.

## • Behavioural treatment of sleep disorders

Kodak T, Piazza CC. Assessment and behavioural treatment of feeding and sleeping disorders in children with autism spectrum disorders. *Child Adolesc Psychiatr Clin N Am.* 2008;17(4):887-905.

# • Pharmacotherapy for sleep problems in ASD and ADHD

Johnson KP, Malow BA. Sleep in children with autism spectrum disorders. Curr Treat Options Neurol. 2008;10(5):350-359.

Corkum P, Davidson F, MacPherson M. A framework for the assessment and treatment of sleep problems in children with attention-deficit/hyperactivity disorder. *Pediatr Clin North Am.* 2011;58(3):667-683.

Weiss SK, Garbutt A. Pharmacotherapy in pediatric sleep disorders. Adolesc Med State Art Rev. 2010;21(3):508-521.

dose, timing, and formulation of medication and the impact on sleep when treating children with NDDs and insomnia.

Pharmacotherapy for sleep problems in ADHD and ASD. It is important to note that medications targeting sleep have not been researched for effectiveness in children and there are no currently approved medications for insomnia in children. A review of this topic is beyond the scope of this article. The Resources section includes references for detailed information on pharmacotherapy for sleep problems in ADHD and ASD, as well as how medications for sleep disorders in NDDs can be used in conjunction with behavioural interventions.

## Review of sleep problems and ASD

Vriend JL, Corkum PV, Moon EC, Smith IM. Behavioural interventions for sleep problems in children with autism spectrum disorders: Current findings and future directions. J Pediatr Psychol. 2011;36(9):1017-1029.

 Combining pharmacotherapy with behavioural therapy

Hollway JA, Aman MG. Pharmacological treatment of sleep disturbance in developmental disabilities: A review of the literature. Res Dev Disabil. 2011;32(3):939-962.

## Tools for evaluation and treatment

## Practice pathway

Malow BA, Byars K, Johnson K, et al. A practice pathway for the identification, evaluation, and management of insomnia in children and adolescents with autism spectrum disorders. *Pediatrics*. 2012;130(Suppl 2):S106-S124.

 Screening checklist for medical comorbidities associated with sleep problems Reynolds AM, Malow BA. Sleep and autism spectrum

disorders. Pediatr Clin North Am. 2011;58(3):685-698.

- This checklist was developed for the Autism Treatment Network as a screening tool for medical issues that might have a negative effect on sleep. Clinicians can use it when they interview families.
- Sleep tool kit from Autism Speaks (booklet for parents)

http://www.autismspeaks.org/science/resourcesprograms/autism-treatment-network/tools-you-canuse/sleep-tool-kit

## Sleep Attitudes and Beliefs Scale

Bessey M, Coulombe JA, Smith IM, Corkum P. Assessing parental sleep attitudes and beliefs in typically developing children and children with ADHD and ASD. *Children's Health* Care. 2013;42(2):116-133.

 This scale was developed to assess parental beliefs about the nature, modifiability, and potential response to treatment of their children's sleep problems. It may be of therapeutic use in identifying and targeting parents' negative beliefs about helping to treat their children's sleep problems.

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**Disclosures:** The authors have stated that they have no disclosures to report in association with the contents of this issue.

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## This activity is supported by an educational donation provided by Meda Valeant Pharma Canada Inc.

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