Overview

This document is a summary of the American Academy of Neurology (AAN) practice guideline “Treatment for Insomnia and Disrupted Sleep Behavior in Children and Adolescents with Autism Spectrum Disorder.” This is a summary of a draft guideline manuscript. The draft guideline is still in development and has not yet been approved by the AAN Board of Directors.

Most sleeping problems in children and adolescents with autism spectrum disorder (ASD) have to do with getting to sleep, waking up during the night, and waking up too early in the morning. The aim of this guideline is to offer guidance about different types of treatments that have been used to help improve these sleep problems in children and adolescents with ASD.

Autism spectrum disorder is a condition that affects the brain in a way that can create challenges in learning and relating to other people. The effects of ASD are different in each person, and they also range from mild to severe.

In children and adolescents with ASD, especially among those with severe symptoms, sleep disturbances are somewhat common. There are many sleep disturbances that can lead to a poor quality of sleep. These include:

- Problems getting to sleep
- Problems staying asleep
- Problems getting enough quality sleep while you’re asleep
- Problems getting to sleep and waking up at the same time day-to-day

Unlike in typical development, insomnia in children and adolescents with ASD does not seem to get better. Poor quality of sleep can make symptoms of ASD worse and even affect daytime behavior, which can have an impact on all family members.

Different treatments have been used to help children and adolescents with ASD get a better quality of sleep. Some of the treatments that have been studied include:

- The use of the drug melatonin
- Talk therapy (known as cognitive behavioral therapy)
- Instructions for parents about teaching better sleep habits
- Weighted blankets

The authors of this guideline use information from the most reliable studies to measure how and for which sleep disturbances these treatments are effective. Then they offer guidance to clinicians, patients, and their families who may consider using these treatments.

What is a practice guideline?

A practice guideline is a document that makes recommendations (guidance statements) for clinicians (doctors and other health care professionals) regarding the use of tests to diagnose or therapies to treat a specific disease or disorder. Recommendations in practice guidelines are based on a thorough review of the medical research. The complete practice guideline describes this review of the medical research and the background for each recommendation. This guideline is in development and has not been published in final form.

What are guideline recommendations and how are they determined?

Guideline recommendations are meant to help guide clinicians when they are partnering with patients and available family members to make decisions about medical care.

When guideline authors write recommendations, they consider:

- The best medical research evidence available
- The balance of potential benefit and potential harm of following the recommendation
- The anticipated result of following the recommendation (how important is the outcome that will result from following the recommendation)
- The cost and availability of the test, therapy, or other subject of the recommendation
- The values and preferences of the patient
Terms used in this guideline

- **Behavioral strategies**—Behavioral strategies include plans to help change a behavior that is causing a problem. In this guideline, the behavioral strategies focus on changing behavior that leads to poor sleep.

- **Bedtime resistance**—Bedtime resistance can be many things a child does to delay falling asleep. This can be refusing to go to bed, stalling to avoid bed, and requiring a parent to take them to bed and then stay in the bedroom.

- **Cognitive behavioral therapy (CBT)**—CBT, or talk therapy, helps you to develop ways to change unhelpful thoughts, feelings, and behaviors that may be the cause of or that may lead to the cause of a problem that you have.

- **Complementary and alternative medicine (CAM)**—CAM are therapies that are used in addition to, or instead of, traditional Western medicine.

- **Insomnia**—Insomnia is being unable to sleep or experiencing abnormal periods of wakefulness.

- **Melatonin**—Melatonin is a hormone that your body naturally makes. It helps your body regulate when you feel ready to go to bed and ready to wake up. Synthetic, or man-made, melatonin is a drug that is taken to help fall asleep and stay asleep longer.

- **Sleep continuity**—Sleep continuity is sleep that is not interrupted by waking up.

- **Sleep disturbances**—Sleep disturbances can be one or more factors that contribute to a poor quality of sleep. The factors discussed in this guideline are trouble getting to sleep, trouble staying asleep, and short sleep periods.

- **Sleep onset latency (SOL)**—SOL is the amount of time between when you get into bed and try to fall asleep and when you actually fall asleep.

What the research shows

The recommendations are summarized in the following sections. The strength of the recommendations is based on the factors listed in Table 1.

**Improving sleep overall**

Many factors of home life can affect how a child with ASD sleeps. Promoting good sleep habits with behavioral strategies is considered the first treatment for all children and adolescents, including those with developmental disorders. When behavioral strategies do not work, clinicians often prescribe melatonin or other medications. There are no studies of the safety of melatonin for long-term use in children and adolescents. However, there is no evidence that short-term use of melatonin in children and adolescents is unsafe. It should be noted that over-the-counter forms may vary in concentration, unlike prescription melatonin.

The guideline recommends that clinicians should first talk with parents and guardians of children and adolescents with ASD about changing habits to improve sleep (Level B). If changing sleep habits does not work and the clinician has checked for and treated any other conditions that could affect sleep or general health, clinicians then should consider prescribing a low dose of melatonin for a short term (Level B). However, the melatonin should be a high-purity pharmaceutical-grade form (Level B).

**Improving SOL and bedtime resistance**

There is a lot of evidence for the effectiveness of CBT and the use of melatonin to help improve SOL in children and adolescents who have ASD, as well as those who do not.

The guideline recommends that clinicians may offer behavioral strategies to help improve SOL in children with ASD (Level C) and melatonin for children with ASD who have no improvement from behavioral strategies (Level B). For bedtime resistance, clinicians should offer behavioral strategies (Level B).

**Improving sleep continuity**

For some people with ASD, staying asleep is a bigger problem than getting to sleep. Sleep continuity can be disrupted by the number of times a person wakes up after sleep as well as the amount of time they stay awake between periods of sleep in a night.

The guideline recommends that to improve sleep continuity in children with ASD, clinicians may offer behavioral strategies (Level C) and may offer controlled-release melatonin either alone or along with CBT (Level C) but may not offer the use of a weighted blanket (Level C).

**Improving daytime behavior through treatments for improved sleep**

Sleep disturbances in children with ASD are also likely to have a negative effect on their daytime behavior. Improving sleep quality may help to improve these behaviors. However, the evidence reviewed does not show that treatment of poor sleep with the use of either weighted blankets or melatonin improves daytime behaviors.

This guideline recommends that clinicians should tell parents and caregivers of children with ASD that treating their sleep disturbances may not improve their daytime behavior (Level B). Clinicians may also talk with parents and caregivers about healthy sleep habits and encourage their use to improve daytime behaviors (Level C).
Table 1. Definitions for Recommendation Levels

<table>
<thead>
<tr>
<th>Recommendation Level</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td>A (Strong)</td>
<td>There are very strong and compelling reasons to follow this recommendation, it possible to follow this recommendation in almost all circumstances, and, in almost all circumstances, patients would want the course of action described in the recommendation to be followed.</td>
</tr>
<tr>
<td>B (Moderate)</td>
<td>There are good and compelling reasons to follow this recommendation, it is generally possible to follow this recommendation, and, in most circumstances, patients would want the course of action described in the recommendation to be followed.</td>
</tr>
<tr>
<td>C (Weak)</td>
<td>There are reasons to follow this recommendation, but the research supporting this recommendation is weak, the benefits relative to the risks are less certain, the test or treatment is costly, or only some patients would want the course of action described in the recommendation to be followed. Recommendations can be “weak” for a variety of different reasons and these reasons are described in the complete guideline.</td>
</tr>
<tr>
<td>U (None Made)</td>
<td>There is not enough research to make a recommendation and/or the balance of the benefits, harms, and costs is unknown.</td>
</tr>
<tr>
<td>R (Research Setting Only)</td>
<td>There is not enough research to make a recommendation and/or the balance of the benefits, harms, and costs is unknown, but there is a good reason to think that more research should be done. Only patients in a research study would receive the course of action.</td>
</tr>
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This summary was created as a tool for people without a medical background to better understand the information in the full document. People can refer to this summary when they provide their feedback during the public comment period for this practice guideline. The complete practice guideline is available at AAN.com/practice-guidelines/home/public-comments.

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