



NATIONAL **FRAGILE X** FOUNDATION  
FRAGILE X CLINICAL & RESEARCH CONSORTIUM

*Consensus of the Fragile X  
Clinical & Research Consortium*

# Sleep in Children With Fragile X Syndrome

— For Your Care Team —

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# **Sleep in Children with Fragile X Syndrome**

## ***For Your Care Team***

**Last Updated:** April 2025

### **Introduction by the National Fragile X Foundation**

Health experts frequently remind the general public about the mental and physical benefits of a good night's sleep. However, surveys and research over the past years confirm that many children with Fragile X syndrome (FXS) experience problems with sleep and that these problems can last for many years.

These sleep problems or “sleep disturbances” can make the challenges of caring for a child with FXS even more challenging, as parents and other caregivers deal with their own need for sleep. Fortunately, as professionals have gained a better understanding of these sleep problems, interventions have been developed that can lessen their severity. These interventions include the use of medication, prescribed and monitored by doctors, and various other interventions that involve behavioral therapists and other non-medical specialists.

The authors of this document, with input from other members of the Fragile X Clinical & Research Consortium, have provided detailed descriptions of sleep disturbances, analysis of current and past research related to those with FXS and other neurodevelopmental disorders, and recommended interventions. Parents and other care providers may want to share this document with their child's doctor and others involved in day-to-day care. In particular, the section on treatment should be reviewed.

Parents can be hopeful that the quality of their child's sleep will improve over time. Some of that improvement will occur as the result of the typical techniques that all parents utilize (bedtime routines, nightlights, comfort and security items), but in the case of FXS, specialist intervention may be necessary.

**Alternate Version:** Please note that a more family-friendly, simplified version of this (and other) recommendations can be found online in our list of [Treatment Recommendations](#) for Fragile X.

## Overview & Consensus of the Fragile X Clinical & Research Consortium

It has been well-established that children with neurodevelopmental disorders (NDDs) have higher rates of sleep disturbances than those in the general population (~25%), reaching a prevalence as high as 80%.<sup>35, 25, 11</sup> Common sleep problems among children with NDDs include difficulties with falling asleep, reduced sleep quality, shorter sleep duration, frequent nighttime awakenings, resistance at bedtime, and daytime sleepiness.<sup>14, 35, 13, 42, 39, 28</sup> These sleep challenges are frequently co-existent and persist across the lifespan. Sleep difficulties in NDDs can be categorized as primary sleep disorders like insomnia and parasomnia, and circadian rhythm sleep-wake disorders.<sup>10, 31, 36</sup>

Sleep problems are also frequent in fragile X syndrome (FXS); however, the range reported by different studies is wide (23%–77%).<sup>2, 9, 16, 17, 29, 38, 17</sup> This variability is most likely due to differences in study design and instruments of assessment. For example, according to parental reports, which included parents of 1,295 children with FXS, 32% of them currently face sleep issues, and, among them, 84% are dealing with at least two sleep problems simultaneously.<sup>17</sup> The most common difficulties reported in this study were trouble falling asleep and waking up frequently at night. Additionally, nearly half of the boys (47%) and a significant portion of the girls (40%) received at least one medication to aid their sleep. Children with more severe health or behavioral challenges were more likely to experience ongoing sleep problems, as in NDDs in general.<sup>3, 20, 23, 32, 35, 41, 42</sup> In another study, caregivers provided information on the sleep patterns of a group of 90 children with FXS using the Children's Sleep Habits Questionnaire (CSHQ), a standardized assessment tool,<sup>27</sup> along with a 14-day sleep diary. The CSHQ results showed that 47% of the participants had sleep issues that suggested the need for further evaluation and referral.<sup>17</sup>

## Profile Of Sleep Problems In FXS

The most recent and largest analysis of sleep problems data, from the [FORWARD project](#), mentioned above, examined their frequency, severity, and impact in a mainly pediatric cohort

of individuals with FXS.<sup>9</sup> This study reported a moderate frequency of ~23%-46% for six of the seven surveyed sleep difficulties. The seventh, sleep apnea, was found to be much less prevalent at 2%-3%. The six surveyed common sleep difficulties involved either sleep duration (i.e., difficulties falling asleep, frequent night-time awakenings) or sleep quality (i.e., morning tiredness, teeth grinding, bed wetting, restlessness). While initial publications have indicated lack of sex differences,<sup>17, 29, 32</sup> the FORWARD survey found that, with exception of snoring, sleep problems affected predominantly young males. These findings are in correspondence with a previous FORWARD study reporting a higher frequency of younger children with FXS treated for sleep problems; 38% and 29%, respectively, for <12 years and >12 years.<sup>15</sup> The large FORWARD study was cross-sectional; therefore, conclusions about evolution of sleep problems in FXS could not be derived. However, a previous investigation found that males seem to improve with age in contrast to females who show relatively stable sleep problems.<sup>17</sup> In addition to sex and age, autistic symptoms are also a risk factor for sleep problems in FXS. The 2017 FORWARD study of autism spectrum disorder (ASD) in FXS cited above found that children and adolescents with FXS and ASD had a higher and relatively stable frequency of treated sleep difficulties than those without ASD (41% vs. 30%).<sup>15</sup> As mentioned above, the study found that sleep difficulties were moderately frequent, up to 46% (children appearing tired in the morning). The group experiencing the highest level of severity (present usually) of sleep problems represented between 6.6% (children struggling at bedtime) and 16.6% (mixed difficulties: children grinding teeth, bedwetting, or appearing restless) of individuals. Caregivers who acknowledged the issues as problematic for the family ranged from ~7% (children snoring loudly) to ~15%-20% (children experiencing other sleep problems).<sup>9</sup>

As noted above, age and sex were relevant factors. Indeed, for five out of the six sleep problems the "present" group was notably younger or comparable to the "absent" group. In contrast, children who snored loudly were older than those who did not. Also, for three of the sleep difficulties (e.g., problems falling asleep) their frequency was higher among males.<sup>9</sup>

Several publications have shown that, in terms of severity, sleep problems in children with FXS tend to be mild to moderate.<sup>9</sup> Nonetheless, the large FORWARD survey demonstrated that their impact is substantial as demonstrated by the high frequency of administration of medications for sleep (i.e., nearly half of individuals, especially males) and the strong association with behavioral problems, in particular irritability/aggression.<sup>9</sup> These FORWARD findings are aligned with a meta-analysis of 26 studies in individuals with NDDs, including

FXS, which showed that a shorter night sleep duration was associated with increased daytime problem behaviors and greater parental stress.<sup>37</sup> One of the previous studies found that, although about 19% of the children were currently using medications to improve their sleep, there were no significant differences in sleep patterns between those receiving drugs and those who were not.<sup>17</sup>

## **Sleep Apnea in Fragile X Syndrome**

Obstructive sleep apnea (OSA) is a sleep disorder characterized by repeated episodes of partial or complete blockage of the upper airway during sleep.<sup>33</sup> These blockages can cause breathing to stop for short periods, leading to disrupted sleep patterns and a decrease in oxygen levels in the blood. While some signs and symptoms of sleep apnea can be similar in both children and adults, there are certain features that are more commonly observed in children: loud and persistent snoring, breathing pauses, restless sleep, mouth breathing, sleeping in unusual positions, etc. It is important to note that not all children with OSA will display all of these characteristics. Additionally, some children may not snore loudly, making the condition harder to identify. If parents or caregivers notice any of these signs or suspect their child may have OSA, it is crucial to consult a healthcare professional for proper evaluation and diagnosis.<sup>4, 22, 6, 26</sup>

OSA can be associated with various neurodevelopmental disorders (NDDs).<sup>42, 30</sup> In a study conducted by Kronk et al., it was found that 38% of children with FXS experienced loud snoring, and 34% had episodes of OSA.<sup>17</sup> Furthermore, findings from the Fragile X Clinical and Research Consortium (FXCRC) database indicated that only 7% of patients were diagnosed with OSA.<sup>16</sup>

The recent FORWARD study found that, according to parental reports, approximately 8% of children with FXS had a history of OSA.<sup>9</sup> However, clinicians reported a lower prevalence of OSA, with only 3.4% of individuals being affected. Notably, these figures for OSA frequency differ significantly from the 30% occurrence of children with loud snoring. The same study revealed a strong link between sleep apnea and intense snoring, along with a weaker but noteworthy association between OSA and morning tiredness or frequent night-time awakenings. In other words, loud snoring, when severe, usually in teenage boys, indicates a high risk for the relatively infrequent OSA.<sup>9</sup> These findings have important implications for the management of children with FXS, as OSA may be underdiagnosed particularly in patients

with more challenging behaviors. It's worth considering that individuals with less severe snoring symptoms may still have OSA, especially if it presents as gasping rather than snoring.

## Diagnosis of Sleep Difficulties

In line with advances in the field of pediatric sleep disorders, the diagnosis of sleep problems in individuals with NDDs has evolved from informal reports by caregivers to the use of standardized instruments.<sup>35, 8</sup> The most important tools are standardized questionnaires that cover a wide range of sleep difficulties. The most widely used is the CSHQ.<sup>27</sup> There are also specialized questionnaires, which focus on certain age ranges (e.g., adolescents [Cleveland Adolescent Sleepiness Questionnaire, CASQ]) or specific sleep difficulties (e.g., daytime sleepiness [Pediatric Daytime Sleepiness Scale (PDSS)], abnormal breathing during sleep [Sleep Related Breathing Disorder subscale from the Pediatric Sleep Questionnaire, PSQ] (for questionnaires, see Bruni et al., 2025)).<sup>8</sup> The CSHQ has been used to characterize sleep problems in FXS and for the evaluation of response to treatment in drug trials. However, its clinical use has been rather limited. Despite their pediatric orientation, questionnaires like the CSHQ are useful for the evaluation of sleep problems in adults with NDDs. Their implementation in other NDDs also allows comparisons and better interpretation of scores in individuals with FXS. The current version of the FORWARD project (FORWARD-MARCH) has incorporated the CSHQ to the assessment of sleep problems, which will lead to additional data for the use and interpretation of this and other sleep questionnaires in FXS. While some questionnaires include the evaluation of the impact of specific sleep abnormalities, a complete characterization of consequences on the quality of life of the individual and the family may require the use of specific instruments.<sup>28, 8</sup>

Polysomnography (PSG), commonly termed sleep studies, are assessments that record multiple physiological parameters during sleep, usually at night, including brain activity (EEG), eye movements, muscle activity (EMG), cardiac rhythm (ECG), and respiratory parameters. In FXS, PSG is mainly used for evaluating breathing problems during sleep (i.e., sleep apnea). Wearables, like actigraphy devices and watches that record activity and heart rate, are beginning to be employed for diagnosing sleep difficulties. However, these devices are still considered experimental tools in NDDs.<sup>8, 28</sup>

## **Impact of Sleep Problems: Behavioral Abnormalities and Quality of Life**

Sleep problems in individuals with FXS can be a significant problem for families/caregivers. In the recent FORWARD study, caregivers who acknowledged them as problematic for the family ranged from ~7% (children snoring loudly) to ~15%-20% (children experiencing other sleep difficulties). For three of the investigated sleep difficulties (e.g., difficulty falling asleep), based on the proportion of reports indicating a problem was usually present versus a problem was a family concern, severity was greater than impact. For the other three sleep problems (e.g., frequent nighttime awakenings), family impact was higher than severity.<sup>9</sup> Sleep problems requiring treatment occur more frequently in adolescent/young adults with FXS and ASD than in their counterparts without ASD. In contrast, sleep problems requiring treatment occur with equal frequency in children with FXS with and without co-occurring ASD.<sup>15</sup> As mentioned above, a previous study found that there were no significant differences in sleep patterns between those receiving drugs and those who were not.<sup>17</sup>

The recent FORWARD investigation showed that sleep difficulties are associated with behavioral problems in individuals with FXS. Indeed, presence of any of the sleep problems was more frequently associated with the occurrence of irritability and aggression. All sleep problems, except morning tiredness, were also associated with hyperactivity. Interestingly, anxiety was only associated with loud snoring.<sup>9</sup> Self-injurious behavior in males with FXS has been associated with a number of co-occurring conditions including sleep problems.<sup>38</sup> The findings in FXS are aligned with those in children with idiopathic ASD, in whom poor sleep, particularly at the moderate to severe level, has also been shown to be associated with increased daytime behavior problems such as irritability, hyperactivity, aggression, as well as internalizing behaviors such as self-injurious behaviors, anxiety, and depression.<sup>12, 19</sup>

While the FORWARD database did not investigate whether sleep disturbances were the cause of the behavior concerns in individuals with FXS, or a consequence of the behavior problem, there is some data from other populations that behavior can improve with treatment of a sleep disorder. In a study using an extended-release preparation of melatonin, increases in sleep duration in children with ASD was associated with improvements in behavior.<sup>34</sup> Tran et al. (2005) showed that treatment of obstructive sleep apnea in typically developing children improved behavior.<sup>40</sup>

# Treatment of Sleep Problems in Fragile X Syndrome

The recommendation of treatments for sleep problems in children with FXS presented here are not primarily based on data on the disorder but rather from recent reviews for ASD or NDDs in general.<sup>8, 5, 36</sup>

## Non-Pharmacological Treatment

The initial approach to addressing sleep difficulties involves applying behavioral techniques (sleep hygiene). These include establishing regular sleep times, following consistent bedtime rituals, and using calming methods for both going to bed and waking up in the middle of the night.<sup>24, 36, 8</sup> Nonetheless, these techniques might not always be enough, and in some cases, using medication alongside these strategies could be necessary.

## Pharmacological Treatment

If behavioral strategies alone are not effective, medications are suggested.

**1. Melatonin:** Melatonin is the first-choice drug for sleep issues because of its largest body of evidence. It is a safe option, although drowsiness, dizziness, headaches, and increased enuresis have been reported. Meta-analyses of clinical trials have demonstrated that melatonin is effective for sleep-onset insomnia, increasing overall sleep time, but does not decrease nocturnal awakenings (maintenance insomnia).<sup>1</sup>

Treatment with melatonin should be initiated at the lower range for the patient's age, with weekly increases if needed. Prescription preparations are more reliable than over-the-counter ones. Melatonin comes in two forms: short-acting (immediate release), which is indicated for sleep-onset insomnia, and long-acting (extended release) for improving night awakenings. It should be prescribed 30 to 60 minutes before someone wants to sleep. Usual dosages are for immediate release 3 to 10 mg, and for extended release 2 to 5 mg.

**2. Clonidine:** If melatonin is ineffective, the most commonly used alternative is clonidine, an alpha adrenergic agonist. It is available in multiple formulations, including extended-release and transdermal patch. Initial recommended dose at bedtime is 25 to 50 microg, with increases every 1-2 weeks up to a maximum, depending on weight, of 0.2 mg per day in children and 0.4 mg in adults. It is worth noting that over time, their effectiveness may diminish, potentially necessitating higher doses to achieve the same outcome. Clonidine



appears to be effective for night waking, sleep latency, and sleep duration, and, because of its behavioral effects, it should be considered for children who also present with behavioral symptoms. Clonidine is in general well tolerated, its side effects include daytime drowsiness. If needed to be discontinued because of adverse effects or lack of efficacy, clonidine should be down-titrated slowly over 2 to 7 days.<sup>5</sup>

**3. Trazodone:** Trazodone, an antidepressant, can also be used at bedtime. Initial recommended dose at bedtime is 1 to 2 mg/kg, with potential increases every 2 weeks up to a maximum, depending on age, of 100 to 200 mg daily in children, and 300 mg for adults. Although typically well tolerated, trazodone might make individuals feel tired, and, sometimes, it can rarely lead to lasting erections.<sup>5</sup>

**4. Other Drugs:** Diphenhydramine and hydroxyzine are suggested for short-term use. Please, note that some individuals may become hyperactive on diphenhydramine. In addition, hydroxyzine can be used for both sleep and anxiety throughout the day. In general, dosing of these medications depends on age and weight. If all medications mentioned do not work, mirtazapine could be introduced.<sup>8</sup> Mirtazapine is an antidepressant medication that can be taken at a bedtime dose of 7.5 mg by both children and adults. Side effects include increased appetite and body weight.

Other alternative drugs include gabapentin, atypical antipsychotics (risperidone, quetiapine), and hypnotics (clonazepam, zolpidem, temazepam, suvorexant). They are reviewed by Blackmer and Feinstein (2016).<sup>5</sup>

## **Complementary and Alternative Interventions**

These include massage therapy, aromatherapy, and weighted blankets. The few studies that have investigated these treatments do not support their usefulness,<sup>20</sup> although the latter are well tolerated.

## **Conclusions**

Data from the FORWARD project and the literature supports the notion that, as in other NDDs, sleep problems are frequent and impactful in FXS. These findings emphasize the need for early diagnosis, and tailored interventions in groups at particularly high risk, namely young children, males, and those with severe autistic behavior. Accurate diagnosis of sleep problems

in FXS requires the incorporation of specialized tools, such as standardized questionnaires. We recommend the use of the CSHQ, considering the available FXS data on this instrument. In those with a concern about sleep apnea, a referral to a center performing PSG and other relevant evaluations is highly recommended.

Considering the complex interplay between sleep, behavior, and family dynamics in a disorder like FXS, we recommend evaluating all these factors when making therapeutic decisions. This will increase the chance to achieve sustained positive outcomes.

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**Author Note:** This document was updated by Walter Kaufmann, MD, Dejan Budimirovic, MD and Dragana Protic, MD, PhD, extensively using the latest published work on the topic by the FORWARD Consortium group: Budimirovic al., “Sleep problems in fragile X syndrome: Cross-sectional analysis of a large clinic-based cohort.”<sup>9</sup> The group used the original document authored by Rebecca Kronk, PhD, CRNP. It was reviewed and edited by both internal and external members of the Fragile X Clinical & Research Consortium and represents the current consensus of the consortium members.

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**The National Fragile X Foundation’s Fragile X Clinical & Research Consortium** was founded in 2006 and exists to improve the delivery of clinical services to families impacted by Fragile X and to develop a research infrastructure for advancing the development and implementation of new and improved treatments. Please contact the National Fragile X Foundation for more information at 800-688-8765 or [visit fragilex.org](https://www.fragilex.org).