Complex Child E-Magazine

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When Your Child Won't Sleep

by Susan Agrawal

My daughter, who is diagnosed with cerebral palsy and several other conditions, had a terrible time with sleep during her first three years of life. She was one of those kids who rarely slept more than an hour at a time, screamed through much of the day and night, and only took short catnaps. Her sleep problems were severe and unrelenting, and after years of sleep deprivation—both hers AND mine—I knew something needed to be done.

It turns out that sleep problems are very common among children, and studies show that as many as one in three children has sleep problems or a sleep disorder.[1] Sleep problems are even more common in children with special needs, especially children like my daughter who have neurologically-based disorders, such as autism, cerebral palsy, or cognitive impairment. As many as 80% of these children may experience sleep problems.[2]

Children who are sleep-deprived, as well as their similarly sleep-deprived parents, can suffer grave consequences. Their mood, behavior, and development are often affected dramatically, causing irritability, hyperactivity, and other negative behaviors during the daytime hours. In addition, their physical health, including seizure regulation, immune system strength, and cardiovascular health, may be negatively impacted by poor sleep and sleep deprivation.

Children with special needs often have multiple reasons for sleep problems. Some may be neurological in nature, as brain injuries or epilepsy may cause changes in sleep state regulation and brain waves. Others are the result of various associated medical conditions, such as breathing problems while asleep, restless legs and other movement disorders, pain, discomfort from reflux and other issues, or severe visual impairment. In some children, behavioral and sensory disorders make sleep difficult.

Regardless of the cause, sleep problems need to be dealt with, both for your child's health and your own. There are three main steps in addressing sleep problems:

- Creating a sleep diary
- Improving sleep hygiene
- Solving medical and behavioral issues

Creating a Sleep Diary

The first step in improving your child's sleep is to identify what problems or issues are contributing to your child's inability to sleep. The best way to do this is to create a two-week sleep diary. Once you analyze the results, you likely will be able to see the specific issues making sleep difficult for your child.

Your sleep diary needs to include a lot of information, including a catalog of daytime naps, daytime sleepiness level, a description of the bedtime routine, a summary of how the child fell asleep, a catalog of any night awakenings, and a calculated length of sleep. It is particularly important to note any medical or behavioral problems you see or suspect, including things like snoring, crying, talking in sleep, episodes of breath-holding, vomiting, jerking or other movements, sweating or hot/cold body temperature, indicators of pain, urination/defecation, and so forth. Below is a sample of a sleep diary.

Sleep Diary

Day _____

Daytime Sleepiness (5 point scale)
1 Wide awake all day
2 Occasionally sleepy
3 Frequently sleepy
4 Falling asleep all day long
5 Excessive napping

Daytime Nap 1
Time of nap _____ Length of nap _____ Where child slept _____
Fell asleep (easily) (with some difficulty) (with great difficulty)
Medical/behavioral concerns:

Daytime Nap 2
Time of nap _____ Length of nap _____ Where child slept _____
Fell asleep (easily) (with some difficulty) (with great difficulty)
Medical/behavioral concerns:

Daytime Nap 3
Time of nap _____ Length of nap _____ Where child slept _____
Fell asleep (easily) (with some difficulty) (with great difficulty)
Medical/behavioral concerns:

Bedtime Routine
Time bedtime routine began _____ Length of bedtime routine _____
Sound level during routine (low) (medium) (high) (very high)
Light level during routine (very dark) (dark) (low light) (light) (very light)
Contents of bedtime routine:

Going to Sleep
Time child put down to sleep __________ Time child fell asleep __________
Length of time it took child to fall asleep __________
Where child slept __________
How child fell asleep (with physical contact of parent) (with parent in room) (by self)
How easily child fell asleep (easily) (with some difficulty) (with great difficulty)
Medical/behavioral concerns:

Night Wakenings
Time of wakening __________ Length of time awake __________
How child woke up ______________________________
How fell back to sleep (with physical contact of parent) (with parent in room) (by self)
Medical/behavioral concerns:

Time of wakening __________ Length of time awake __________
How child woke up ______________________________
How fell back to sleep (with physical contact of parent) (with parent in room) (by self)
Medical/behavioral concerns:

Time of wakening __________ Length of time awake __________
How child woke up ______________________________
How fell back to sleep (with physical contact of parent) (with parent in room) (by self)
Medical/behavioral concerns:

Time of wakening __________ Length of time awake __________
How child woke up ______________________________
How fell back to sleep (with physical contact of parent) (with parent in room) (by self)
Medical/behavioral concerns:

Time of wakening __________ Length of time awake __________
How child woke up ______________________________
How fell back to sleep (with physical contact of parent) (with parent in room) (by self)
Medical/behavioral concerns:

Waking Up
When child woke up for the morning __________
How child woke up ______________________________
Total time asleep for the night __________
Sleep quality (very poor) (poor) (adequate) (good)
Medical/behavioral concerns:

Improving Sleep Hygiene

"Sleep hygiene" is a term doctors use to describe the acts associated with healthy sleep practices. In general, it includes four subtopics: the sleeping environment, the sleep schedule, sleep routines, and extrinsic factors (such as meals or caffeine use).[3] Sleep hygiene is extremely important whether or not your child has special needs, but for children with special needs, it is even more critical. Sleep hygiene can easily be changed and improved, whereas medical and behavioral issues encountered by children with special needs are often much more difficult to treat.

Both parents and doctors often forget how important sleep hygiene really is. Simply analyzing and improving sleep hygiene can eliminate the vast majority of sleeping problems.

The **Sleep Environment** includes everything surrounding your child as she sleeps, such as where she sleeps, the softness of her mattress, her blankets and pillows, the angle of her bed, the temperature of her room, the position she sleeps in, and the sound and light in her room. Changing these parameters can make an enormous difference for some children. For example, a child with cerebral palsy who cannot move on her own may struggle to sleep on a firm mattress on her back. A memory foam mattress topper and positioning pillows that prop her onto her side may dramatically improve sleep. Changing her position every few hours may also make a big difference. Angling up the head of the bed may help to treat reflux and improve sleep, especially for children who receive feedings during the night.

Safe sleeping is also important. Some children may require a bed with high sides or mesh to prevent escape at night. Others may need padded bedrails in case of seizures. Children with limited volitional movement need beds that will not entrap their arms, legs, or head while they are sleeping.

The temperature of the room is often overlooked. Some children with neurological issues tend to get very, very cold at night. Keeping these children warmer with extra layers, hats and mittens, microwaved stuffed animals, and hot water bottles may improve sleep considerably. Other children tend to overheat at night, and may need fans, air conditioners, cooling packs, and other similar inventions, along with breathable or absorbent sheets.

Children with sensory difficulties may respond either positively or negatively to blankets. Some find them intolerable, while others want heavy weighted blankets covering them for security or sensory input. Some children, even older children, sleep better if they are swaddled up in their blankets. Similarly, some children react really well to white noise machines or other auditory distracters, while others prefer music or silence. In some cases, certain children need complete sensory deprivation, with all lights, sounds, and visual stimuli removed.

The darkness level of the room can also be problematic. While some children fear the dark, others require darkness to sleep. Children with visual impairments who have little ability to sense light may be particularly sensitive in this regard. It may be beneficial to expose these children to very bright light during the day and complete darkness at night.

The **Sleep Schedule** is also extremely important, as children's bodies have natural circadian rhythms that govern sleep and wake cycles at approximately the same time each day. If sleep does not occur within these rhythms, sleep disorders often develop. Some children also have unusual, disrupted or altered circadian rhythms that make sleeping very difficult. Children who are blind, have epilepsy, or nap frequently due to fatigue may be particularly prone to disruptions of their circadian rhythms.

It is absolutely vital to keep a consistent sleep schedule for children with special needs. This means that a child should always go to bed at the same time and ideally should wake up at about the same time each day. Naps should also be scheduled as much as possible. Bedtime should never vary by more than an hour.

Many children do remarkably well with an early bedtime. Almost all children naturally want to fall sleep between 6:30 and 8:00pm. If your child is staying up later than 8:00pm, consider moving his bedtime earlier. You may find he sleeps much better.

If your child is falling asleep late at night or has day and night reversed, it is best to use a gradual technique to slowly move his bedtime to a more reasonable time. Going to bed 15 minutes earlier (or later) each night is often the best strategy. Over a week or two, even a night owl may be able to fall asleep much earlier. In some cases, a short course of medication may help shift the sleep schedule to a more appropriate one.

Bedtime Routines are important for all children, and are especially critical for children with cognitive impairments or other disabilities that respond well to routine. The general recommendation for all children is to include a calm hour for winding down prior to bedtime. Many families use this time for baths, massages, reading stories, listening to calm music and cuddling. It is also a time for low lighting and quiet. At first, it is probably best to create a highly structured bedtime routine that is identical from night to night. As your child learns to sleep better, you may be able to relax the routine somewhat.

Children vary dramatically when it comes to what items or routines they find calming. Some find a favorite television show to be calming, while others become highly stimulated with television. Baths may be calming for some children, while others may get all excited splashing around. You likely already know what works for your child.

Using sleep cues can be very helpful. These might include a favorite stuffed animal or blanket, playing or singing the same music each night, repeating a sleep "mantra" such as "nighty-night, sleep tight," reading the same book each night, or saying the same prayer nightly. Choose two or three sleep cues to use every night as part of your calming routine.

Many children with special needs have great difficulty soothing themselves. Many are physically unable to use normal calming techniques, such as sucking a pacifier or thumb, or grabbing a favorite stuffed animal. Some have become accustomed or reliant on parent-provided soothing techniques, such as rocking, massaging, and cuddling. Many will only sleep with a parent. While it is ideal for children to learn to fall asleep by themselves, this can be very hard for many children with special needs. It is often best to work on this technique at bedtime, and in time it may carry over into nighttime wakings.

Extrinsic Factors include daytime activities that impact on sleep. These may include meals, exercise, and medications, among others. For example, it is not wise to give a very large feeding right before bed, as this is likely to disrupt sleep. On the other hand, hunger may also disrupt sleep, so a light snack may be useful. Medications and certain foods, such as drinks containing caffeine or stimulant medications, may make it difficult for children to fall asleep. It may be wise to adjust feeding and medication schedules to promote sleep, with larger feedings and stimulant medications given early in the day, and smaller or slower feedings and drowsy medications given in the evening.

If you have made your sleep diary, now is the time to analyze it in relevance to sleep hygiene. You are likely to see trends, both in regards to techniques that are working and practices that are not working.

Solving Medical and Behavioral Issues

Once you have established a good sleep routine, appropriate sleep schedule, and a comfortable sleeping environment, it is time to move on to medical and behavioral issues that impact sleep. Children who still won't sleep after improving their sleep hygiene typically need to see a sleep specialist or behavioralist for more specialized help.

A sleep specialist should be able to identify whether certain medical conditions are impacting sleep. Many of these are respiratory issues, including an airway obstructed by large tonsils and adenoids, a floppy airway, central apnea, or hypoventilation. Children with these conditions may need surgery or treatment with breathing devices (CPAP, BiPAP, oxygen, or ventilation). Other conditions that need optimal treatment to promote sleep include reflux, epilepsy, pain, and movement disorders.

Children who have difficulty falling asleep may benefit from a trial of melatonin, which is generally considered safe in children, although it may lower the seizure threshold for some children. In general, melatonin works best for sleep-onset problems, but only when there is a problem with melatonin secretion or disrupted circadian rhythms.

Other medications are available to help children sleep, but these should only be used under the strict guidance of a sleep specialist. These may include benzodiazepines, barbiturates, antihistamines, antidepressants, chloral hydrate, and other medications.[4]

Because these medications can be very dangerous if used incorrectly, it is of vital importance to see a specialist before trying any of them on your own.

Good Sleep is Possible

My daughter is now seven and sleeps very well. She can fall asleep on her own and stays asleep much of the night. While improving her sleep hygiene helped a lot, ultimately she required medication for several months to help her stay asleep through the night. The majority of her problems stemmed from untreated pain and discomfort, and once this was improved, we saw a dramatic improvement in her quality and quantity of sleep.

Good sleep is possible, but it is likely to take a tremendous amount of effort on your part, especially in creating and maintaining sleep routines through the weeks or months it may take for them to work fully. It is definitely worth the effort. You have the choice of putting in a few hard months now, or having neither you nor your child sleep for the foreseeable future. Hard as it may be, do it for both your health and your child's health.

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[1] James E. Jan *et al*. Sleep Hygiene for Children with Neurodevelopmenal Disabilities. *Pediatrics* 2008;122(6):1343-50.
[2] Jan, 1343.
[3] Jan, 1344.
[4] Jan, 1344.