

The Good Night, Sleep Tight WORKBOOK

For Children with Special Needs

TODDLERS TO TEENS



**Gentle Proven Solutions to Help Your Child with
Exceptional Needs Sleep Well and Wake Up Happy**

The Sleep Lady®
KIM WEST^{LCSW-C}
and Katie Holloran^{MA, BCBA, GSC}

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Disclaimer: The information and advice presented in this book have been reviewed by a qualified pediatrician. It should not, however, substitute for the advice of your family doctor or other trained healthcare professionals. You are advised to consult with a healthcare professional with regard to all matters that may require medical attention or diagnosis for your child, and you should check with a physician before administering or undertaking any course of treatment such as sleep training your child.

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Introduction



A key factor that makes The Sleep Lady method so successful is that it's not a "one size fits all" approach to sleep coaching. When we work with individual families we consider their values, lifestyles, and child-rearing philosophies to avoid suggesting they do something they would feel uncomfortable doing, and that would therefore likely be counterproductive. We can't stress this enough: A sleep-coaching plan that parents can't stick to is bound to fail.

It's also important to know that The Sleep Lady Shuffle is not an overnight cure. Essentially, you're teaching your child a new skill. So be patient and remember that mastering a skill—whether it's walking, handling a spoon, using the potty, talking, or sleeping through the night—takes time. However, the families I work with solve the majority of their kids' bedtime snafus within a month. (Issues like napping and early rising often take a little longer.)

How to Use this Workbook

For best results, we recommend reading each section of the workbook that's relevant to you and your child before you begin creating your plan (on page 80.) The workbook is organized to first give you the basics of sleep science (Chapter 1), followed by an overview of The

Sleep Lady Shuffle (Chapters 2, 3, and 4). Note that in Chapter 2, where you'll find recommended sleep guidelines for children from the National Sleep Foundation (NSF) and the American Academy of Pediatrics (AAP), you should read the section that matches your child's developmental and cognitive age, rather than his physiological age. If you aren't sure, ask your child's educational or medical team for guidance.

Next, move on to Chapters 5 and 6 to learn tips and strategies that will help you to customize The Sleep Lady Shuffle to fit your child. If you have specific problems around naps, weaning, or co-sleeping, you'll find help in Chapters 7, 8, and 9, respectively. In Chapter 10, you can create your sleep-coaching plan by reading through the examples and then using the template on page 80. Chapters 10 and 11 offer suggestions for implementing your plan cribside and bedside. We've included troubleshooting tips in Chapter 13 to answer some of the questions parents ask most frequently. And finally, in Chapters 14 and 15, you'll find blank charts to use, plus visuals and information about products that you may find helpful.

Now for a few words of encouragement: Your success in sleep coaching will depend on the same factors you bring to parenting every day—consistency, follow-through, and patience—meaning you're as well-equipped as any expert to guide your child with special needs to sleep success. Do be sure that his other caregivers (your spouse, partner, sitters, medical team, and so forth) are as committed as you are.

May you enjoy many peaceful nights of sleep ahead!

—Kim West, LCSW-C, The Sleep Lady
and
Katie Holloran, MA, BCBA, GSC

Before You Begin Sleep Coaching

Why Sleep Matters



Your child has received a diagnosis from a doctor or clinician and is experiencing problems around sleep in addition to his medical, social, developmental, or emotional needs. It's likely this means he's exhausted, and you and the rest of the household are as well.

Perhaps this is your first stop on the way to finding solutions. Or you've already tried strategies to create better sleep for your child that haven't worked. Either way, you've come to the right place. This workbook will provide research-based information, specific guidelines, action steps, and helpful resources to put you, your child, and your family on the path to better sleep.

The body of research around sleep in general, and specifically around sleep for children with special needs, is relatively new, but it's growing. What is known is that parents of children with special needs report a higher rate of sleep problems than do other parents. In one survey of parents of children with a broad range of disabilities, almost 80 percent reported an issue with their child's sleep. Alarming, one in four of those parents described the sleep problem as "severe."

Sleep problems, including trouble falling asleep, staying asleep, and getting enough sleep, are especially common in children and teens with developmental disabilities. Between 63 and 80 percent of children with developmental disabilities have issues with sleep, compared to 35 to 50 percent of typically developing young children. Children with



Max, age 2

issues such as attention deficit hyperactivity disorder (ADHD) also struggle with sleep problems more frequently than do other children.

Poor sleep or too little sleep can have serious repercussions for all children, including behaviors such as meltdowns, aggression, self-injury, and repetitive self-stimulatory behavior. Sleep problems also can interfere with learning. Children who are developing normally tend to outgrow their sleep issues, but those with special needs often don't and continue to have associated problems into their teen years and even adulthood, such as obesity, behavioral and emotional problems, and anxiety.

Working with Your Team: 11 Things to Do before Starting Sleep Coaching

1. Rule out underlying medical conditions.

Many sleep problems are behavioral, meaning you can teach your child new sleep behaviors through coaching. However, you should have your pediatrician make sure there are no physical reasons your child is having issues. Reflux, ear infections, and allergies can interfere with quality sleep, for example, as can asthma, which causes the airways to become inflamed and swollen. Even what may be described as mild asthma can take a huge toll on a child's sleep. "If mild asthma has swollen your bronchiole tubes just enough to make you breathe a little faster at baseline, then perhaps your sleeping respiratory rate is 18 breaths per minute rather than the normal 14 to 16 BPM . . . Those extra breaths raise your heart rate, lighten your sleep and fracture your sleep architecture," explains Lewis Kass, MD, a board-certified pediatric pulmonologist and sleep medicine specialist in New York.

Similarly, obstructive sleep apnea (OSA), which in kids often is caused by enlarged tonsils and adenoids (but also neurological disorders, bony problems of the face, jaw, and head, and obesity), can prevent a child from getting a healthy night's sleep by blocking the upper airways. According to Kass, during sleep, this blockage is worse because "our airways and our chest wall muscles and our neck muscles go to sleep too . . . The way a child combats this is to do whatever it takes to open up and enlarge the airway. This is accomplished by waking up in order to take a deeper breath. Accordingly, one of the hallmark symptoms of OSA is restless sleeping."

2. Tweak your child's therapy sessions to make time for sleep training.

Once you've decided to move forward with sleep coaching and have settled on a date to get started, contact each of the therapists and other specialists your child sees regularly. This is important not

only because you want to make sure that all aspects of her care complement each other, but also because successful sleep training depends on careful timing, and you may need to reschedule appointments around afternoon naps, say, or switch evening sessions to mornings so they don't happen too close to bedtime. Don't worry about inconveniencing your child's treatment team: Just like you, they want to see your child thrive and are very aware that the better her sleep, the easier it will be for them to give her the help she needs.

3. Review your child's medication.

With his medical team, go over the medicines your child takes regularly to make sure one (or more) of them isn't potentially interfering with his sleep during the day and/or during the night. If this is the case, then the most direct and effective way to address your child's sleep issues may be to change when he takes his medication, or to have him try a different one. Some families talk to their medical professionals about melatonin as well. This is a hormone naturally produced by the body's pineal gland to regulate sleep-wake cycles. While some families have reported success with this as a supplement, make sure to discuss the benefits, risks, and potential side effects with your child's doctor before giving it to him.

4. Keep an activity log.

Because you're exhausted, it's likely your days (and nights) are flying by in a blur, and your short-term memory isn't what it used to be. To find an effective solution to your child's sleep problems, you'll need to get a clear picture of what's happening at bedtime and during the night, what's working, what's not, and how your child is responding. Keep track by writing it all down for a few days or, better yet, a week, before you start coaching. Some parents find it easiest to keep a notebook next to their child's bed. (You'll find a sample log on pages 119–120, but feel free to come up with your own format. Or download

The Sleep Lady's app "Gentle Sleep" for iOS and Android, which will allow you to easily log your child's sleep and also access helpful articles about typical sleep schedules, age-specific tips, and other information.)

Use your log or the app to note when and how often your child wakes up during the night. Include what you did to get her back to sleep, whether you rocked her, nursed her, sang to her, or brought her into your bed. Having such a record to refer to rather than relying on scrambled mental notes in your sleep-deprived brain will give you a more accurate picture of your child's patterns and your own responses, and will allow you to compare your child's daily schedule to the typical schedules outlined in Chapter 2.

Continue the log after you start sleep coaching. Tracking your child's sleep patterns will help you figure out what's working, what's not, and what tactics you should tweak.

5. Determine your child's ideal bedtime.

This is the period of time during which he'll show signs that he's ready to sleep—yawning, rubbing his eyes, twisting his hair, whining. Often parents miss a child's sleep cues, especially in the evening, because it's such a busy time of day. They may be cleaning up the dinner dishes, shuffling through the mail, helping other kids with homework, and so forth. Pay attention to how your child behaves between 6 and 8 p.m. (and make sure he's not zoning out in front of a screen). As soon as he begins acting drowsy, you'll know that that's his natural bedtime and the time at which you should be putting him to bed each evening going forward.

If you have trouble picking up on your child's drowsy signals, you can pinpoint a reasonable bedtime for him by looking at when he normally wakes up and factoring in how much sleep he should be getting based on recommended sleep averages (see pages 8 and 12.) Let's say you have a 2-year-old who tends to wake up by 6 every morning. The average 2-year-old should get 10 to 11 hours of sleep at night, so that means making certain your child has gone through his entire bedtime routine and is *sound asleep* by 8 p.m.

6. Create a relaxing bedtime routine.

Children of all ages need a set of comforting and predictable rituals and routines to help them prepare physically and psychologically for sleep. These activities should be calm, quiet ones, such as reading or being read to, listening to a story, or being sung to. Bedtime is not the time for tickling, wrestling, scary tales, television or other screens, or anything else that's stimulating. Because you're preparing your little one to be separated from you for the night, the tone should be serene and reassuring. With the exception of baths, toileting, and teeth brushing, the bedtime routine should take place in the child's bedroom.

If your child hates some aspect of the bedtime routine, get that part over with first. For instance, if she can't stand brushing her teeth, do it right after her bath, not after you've read two books and she is relaxed and cozy already.

7. Install room-darkening shades.

If your child's bedroom gets too much light, he wakes up very early, or has trouble napping, install room-darkening shades. Leave a dim night-light or closet light on so that you can see him when you check on him.

8. Drown out sleep-disruptive sound.

If your child's room isn't very soundproof and you have a dog that barks a lot, loud neighbors, other children, live on a busy street, etc., consider turning on a white noise machine or a fan, or play white noise or soothing music on your smartphone or other device (there are apps for that). Children do learn to sleep through routine household sounds (and they should to a large extent), but some places are really loud, and some kids are really sensitive. We discourage using music that turns off to mask noise; kids can get too dependent on it, meaning they'll want someone to come in and restart their music every time they wake up.

9. Get your child used to waking up between 6 and 7:30 a.m.

Five days before you start sleep coaching, start waking your child up by 7:30 in the morning at the latest.

10. Get all your child's caregivers on board.

It's vital that your spouse, partner, nanny, and anyone else who regularly takes care of your child understands each aspect of the sleep-coaching plan (and why it's important) and is willing to follow through. This is key to maintaining the consistency that's so vital to sleep success. (See Chapter 7, Nap Coaching, for what to do when you have a reluctant babysitter, and also how to work around your child's schedule if she's in daycare or a school program.)

11. Pick a realistic start date.

Choose a block of time, ideally about three weeks, during which you don't expect any major disruptions or changes in your household, such as trips, moving, or the arrival of a new baby. Some families decide to start sleep coaching during a summer or winter vacation so the grown-ups won't have to juggle sleep training with work. That's a good strategy, but be careful to keep your child's schedule consistent, even if yours is not. For instance, don't introduce a sensible 7:30 p.m. bedtime the very week you plan to let him stay up until 10 p.m. with the grandparents on Christmas Eve, or are going to have a horde of entertaining young cousins camping out in your backyard over the Fourth of July.