

## Sleepless Children and Exhausted Parents -- Understanding Sleep Problems and Exploring Solutions

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### Sleep 101

Why do we sleep?

- Alertness/performance
- Memory, concentration, creativity
- Better health
- Mood

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### Sleep Is Needed To:

- Remember what we learned
- Organize our thoughts
- Engage in tasks of executive functioning
- React quickly
- Work accurately and efficiently
- Think abstractly
- Be creative

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Sleep Regulation

- Homeostatic Drive
- Circadian Rhythms

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Circadian Rhythms

- Occur about every 24 hours
- Include Patterns of
  - Sleeping and waking
  - Activity and rest
  - Hunger and Eating
  - Fluctuations in Body Temperature
  - Hormone Release

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Zeitgebers

- Social Demands
- Time Cues
- Light

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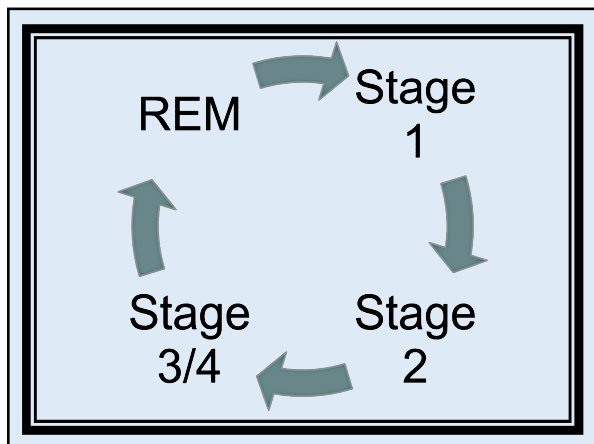
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### Melatonin

- Produced when it is dark
- Pineal Gland
- Light suppresses Melatonin secretion

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Descriptive Category	Age Range	Recommended	May be Appropriate	Not Recommended
Preschool	3-5	10-13	(8-9) or (14)	Less than 8 hours; More than 14 hours
School Age	6-13	9-11	(7-8) or (12)	Less than 7 hours; More than 12 hours
Teenager	14-17	8-10	(7) or (11)	Less than 7 hours; More than 11 hours
Young Adult	18-25	7-9	(6) or (10-11)	Less than 6 hours; More than 11 hours

From the National Sleep Foundation

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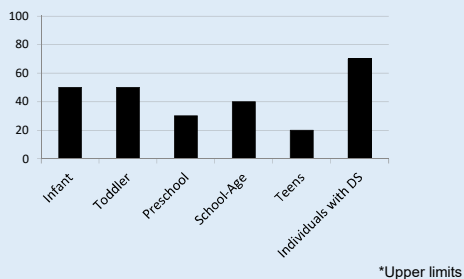
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### Estimates of Sleep Disturbance



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### Common Sleep Difficulties

- Irregular sleep-wake cycles
- Difficulty settling
- Delayed sleep onset
- Night waking
- Short sleep duration
- Early morning wake times

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### Medical Considerations

- Gastrointestinal
- Seizures
- Snoring
- Pain
- Itching
- Nutrition
- Medication

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### Behavioral

- Anxiety
- Arousal dysregulation
- Difficulty calming
- Social cues
- Transitions and change

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### Key Sleep Screening Questions

- Does the individual maintain a regular sleep schedule?
- Does the individual have any problems at bedtime?
- Does the individual have any problems falling asleep?
- Does the individual wake up during the night?
- Does the individual snore?
- Is the individual restless during sleep
- Does the individual have any unusual behaviors during the night?
- Does the individual need help to wake up in the morning?
- Is the individual sleepy or overtired during the day?
- Is there a family history of sleep problems?

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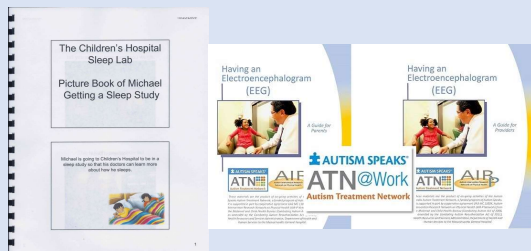
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### Sleep Studies and EEGs



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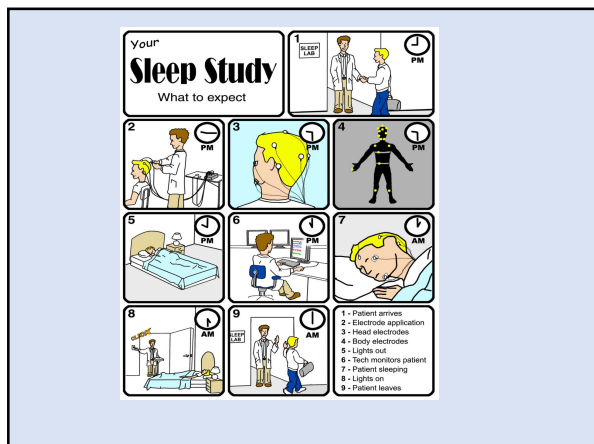
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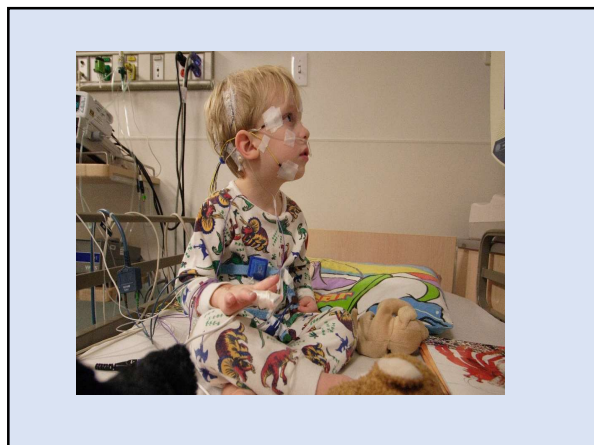
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AAP Healthcare Guidelines

- Baseline sleep study for all children with Down syndrome by age four.
- Monitor sleep patterns in individuals of all ages

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### Down Syndrome and OSA

- Individuals with DS are at risk for OSA
- 50-100% incidence of OSA in individuals with DS
- Incidence increases with age
- Treatment may include remove of adenoids and/or tonsils
- Even after surgery 30 to 40% of children show recurrent or persistent OSA.

(National Down Syndrome Society; Marcus, 1991; Donnelly et al, 2004)

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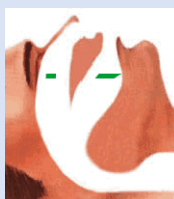
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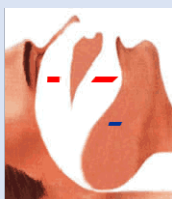
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### Obstructive Sleep Apnea



**Normal Breathing**  
- Airway is open  
- Air flows freely to lungs



**Obstructive Sleep Apnea**  
- Airway collapses  
- Blocked air flow to lungs

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### Why?

- Anatomy
  - Central Apnea
  - Low muscle tone in mouth and upper airway
  - Poor coordination of airway movements
  - Narrowed air passages
  - Relatively large tongue
  - Enlarged adenoid and tonsillar tissues
- Increased upper airway infections
- Higher incidence of obesity

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**Physical Indications**

- Loud, continuous nightly snoring
- Apneic pauses
- Restless sleep
- Sweating during sleep
- Abnormal sleeping position
- Mouth breathing (and dry mouth)
- Chronic nasal congestion
- Morning headaches
- Frequent infections
- Difficulty swallowing
- Poor appetite

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**Behavioral Indications**

- Excessive daytime sleepiness
- Mood changes
- Internalizing behaviors
- Externalizing behaviors
- ADHD-like symptoms
- Learning problems
- Academic problems

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**Sleep Positions**

- Sitting up
- Hyper-extension of the neck
- Bent forward at the waist

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Treatment



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Learning to Use CPAP

- Modeling
- Education
- Desensitization

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Daytime Functioning

- Attention
- Activity level
- Tasks of executive functioning
- Flexibility
- Self-monitoring
- Self-regulation
- Emotional regularity

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### Restless Leg Syndrome and PLMD

- Genetic Link
- Sleep deprivation
- Iron deficiency
- Neurological Disorders
- Medications
- Caffeine
- Drugs and chemicals



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### Delayed Sleep Phase Disorder

- Sleep onset at a consistently late time
- Minimal difficulty with sleep maintenance
- Significant difficulty waking at the required time
- Persistent difficulty going to sleep at an earlier time
- Complaints of insomnia
- Daytime sleepiness

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### Nightmares

- Recurrent episodes of awakening from sleep with **recall** of dream mentation
- Full alertness upon awakening with little confusion or disorientation
- Delayed return to sleep after the episode
- Occurrence of episodes in the latter half of the typical sleep period

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### Parasomnias

- Confusional Arousals
- Sleepwalking
- Sleep terrors



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### Common Characteristics

- Occur early in the night
- Agitation, confusion, disorientation
- Increased agitation with comfort
- Amnesia for the event
- Positive family history
- Exacerbation by insufficient sleep or sleep fragmentation

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### Behavioral Intervention Works!

- Behavioral treatment of bedtime problems and night wakings in infants and young children
  - Behavioral treatment produces reliable and durable changes (80% of children improve)
  - 94% of studies report intervention was efficacious

Mindell, JA, Kuhn, B, Lewin, DS, et al. Sleep, 2006;29:1263-76

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Behavioral Strategies

- Daytime Habits
- Evening Habits
- Sleep Environment
- Sleep Needs and Timing of Bedtime
- Bedtime Routines
- Use of Visual Supports

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Specific Considerations

- Communication
- Social motivation
- Flexibility
- Sensory

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Daytime Factors

- Exercise
- Light
- Caffeine
- Naps
- Bedroom use



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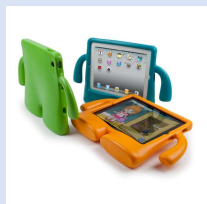
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### Evening Habits

- Limit stimulating activities
- Less light
- Routines



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### Sleep Environment

- Temperature
- Texture
- Sound
- Minimal Light



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### Bedtime Routines

- Consistent bedtime
- Calming activities
- Use of a visual schedule
- Limit electronic sleep aids
- Rituals
- Responses



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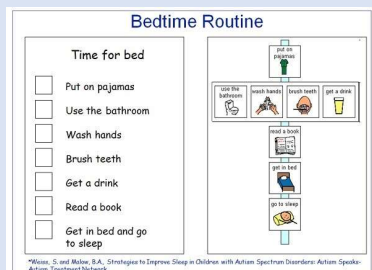
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## Visual Supports




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## Other Visual Strategies

- Schedules with photos
- Object schedules
- Cues in the environment

### Schedule Boards:

Some children are not able to use a visual schedule that uses words, photos, or icons. It may help to use objects instead.

Here's an example: If your child's bedtime routine consists of using the toilet, taking a bath, washing hair, brushing hair, having a massage, and listening to music, you might have a place near the bathroom or bedroom with the following items: a roll of toilet paper, a bar of soap, a bottle of shampoo, a hairbrush, a bottle of lotion, and a CD. Your child would get each object before the start of an activity and use this to guide his or her actions. Save a special object just for bedtime. This might be a special blanket, pillow, or stuffed animal. Once your child has this object, he or she should go into his or her bed. Even if you do not use objects, write down your child's schedule so that you are going through the same steps each night. Use single words or two-word phrases to label what you are doing.




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## Using a Visual Schedule

- Choose one cue to prompt schedule checking
- Use physical prompts rather than verbal prompts
- Physical prompts should be delivered from behind the individual
- Only the individual should manipulate the schedule
- Place schedule in a convenient and central spot
- Display the schedule in the same location every day
- Reward the individual for following the schedule

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### Sensory Strategies

- Rocking and Swinging
- Snuggling
- Massage
- Lotion
- Listening to music
- Calming scents
- Chewing gum, vinyl tubing
- Clothing
- Bedding
- Weighted blankets
- Mattresses
- Bed tents
- Night lights
- White noise

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### Sleep Resistance?

- Not Sleepy?
- Anxious?

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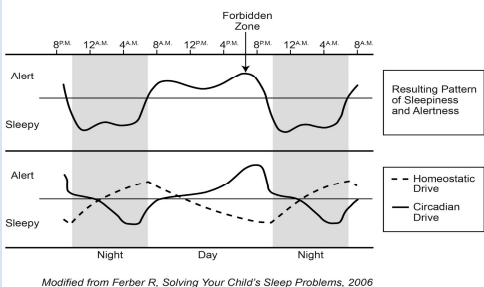
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### Timing of Bedtime is Important!




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### Strategies for Sleep Resistance

- Timing
- Unmodified extinction (cry it out)
- Graduated extinction (checking)
- Fading parental presence (rocking chair)
- Rewards



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### Understanding Night Wakings

- Begin at bedtime (Durand, 1998)
  - Learning how to fall asleep
  - Falling asleep while drowsy



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### What to do?

- Respond quickly to distress
- Brief and boring
- Use of visual aids and social stories
- May get worse before getting better
- Rewards

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### The Bedtime Pass



Friman, Arch Pediatr Adolesc Med, 1999; 153(10): 1027-9

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### Early Morning Awakening

- Different from night wakings
- Consider possibility of depression
- Delay bedtime
- Learning to stay in bed
- Rewards
- Safety



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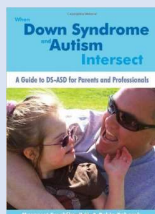
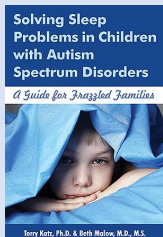
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## Resources



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### AS ATN Toolkits

**Visual Supports and Autism Spectrum Disorders**

**Sample Images for Visual Schedules**


**Checklist for Visual Schedules:**

- Use pictures or symbols that are meaningful to the individual.
- Use a consistent sequence of pictures or symbols.
- Use a consistent color for each picture or symbol.
- Use a consistent size for each picture or symbol.
- Use a consistent background color for each picture or symbol.
- Use a consistent font for any text.
- Use a consistent layout for the schedule.
- Use a consistent order for the pictures or symbols.
- Use a consistent number of pictures or symbols.
- Use a consistent number of rows and columns.
- Use a consistent number of pictures or symbols per row or column.
- Use a consistent number of pictures or symbols per page.
- Use a consistent number of pages.
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