

# **"To Sleep, Perchance to Dream: Sleep Disorders in Rett Syndrome"**

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# Sleep Requirements for Typically Developing Children

- 0-2 months: 16-20 hours; no night/day pattern
- 2-12 months: 9-12 hours
- 1-3 yr: 12-13 hours per 24 hours
- 3-5 yr: 11-12 hours per 24 hours
- 12-18 yr: 9-9.5 hours

# Average Need for Naps

- Newborn to 2 months: 4 naps per day
- 2-12 months: 1 – 4 naps (2 – 5 hours)
- 1-3 yr: 1 – 2 naps
- 3-5 yr: 0-1 naps
- 12-18 yr: 0 naps

# Types of Sleep Disruption



- Wakes up and plays happily in the middle of the night
- Cries and is inconsolable no matter the parent's action
- Wakens and cries until someone comes to hold her, turn on DVD player, or take her to your bed

**Wakes up and plays happily in  
the middle of the night**



# Leave this little lady alone!

- She is entertaining herself. If you interfere, you will teach her that she needs company.

## YOU SHOULD:

- Insure that her room is a safe place to move around.
  - no furniture or other items may be pulled down if she grabbed hold of it.
  - install a gate to the door way
- Your home is clean so no harm is done if she falls back asleep out of her bed

**Cries and is inconsolable no matter the parent's action**



- Identify any medical problems.
- Some medications can interfere with sleep
- Evaluate for possible physical pain or distress:
  - Acid Reflux
  - Constipation
  - Seizures
  - Sleep Apnea
  - Bone injury
  - Gall Bladder Disease

# Gastro-esophageal Reflux Disease or GERD/Acid Reflux

- Acid reflux is the cause of heartburn and it hurts.
- Sleep disruption may be the only symptom.
- A health care professional needs to help you diagnose this problem and treat it.

# Constipation

- Constipation is a lifetime problem for most girls with Rett syndrome.
- As with many health problems, prevention is always the key to constipation.

# Increased Muscle Tone

- Due to an inability to reposition herself, your daughter may need to be repositioned during the night.
- By learning her pattern you can anticipate the waking and reposition her before she begins to cry.

**She Wakens, Cries, and  
Wants You in Her Room...  
NOW**



- After you have established with your medical team that there is no physical reason for her sleep disruption, it's time to teach your daughter the house rules
- She may learn behavioral insomnia of childhood. Sleep onset type (ie: being rocked to sleep, DVD in room)
- She has trained you well. It's time to retrain HER

# Good Bedtime Practices

- Girls with Rett syndrome have difficulty transitioning from sleep to an awake state and returning to sleep.
- By modifying her behavior you can teach her to put herself back to sleep.

# Oh Poor Baby Syndrome

- Your poor baby doesn't understand.
- It's not fair...she already has to deal with having Rett syndrome.
- I can't stand it, I've been up all night listening to her demands.
- Consistency is the name of the game.

- Medication may be considered if these approaches fail or if the family is in crisis.
- It is important to discuss these concerns with your daughter's primary care physician or a sleep specialist.

A good night's sleep promotes learning, improved mood, general health, and an improved quality of life for your child and the whole family

