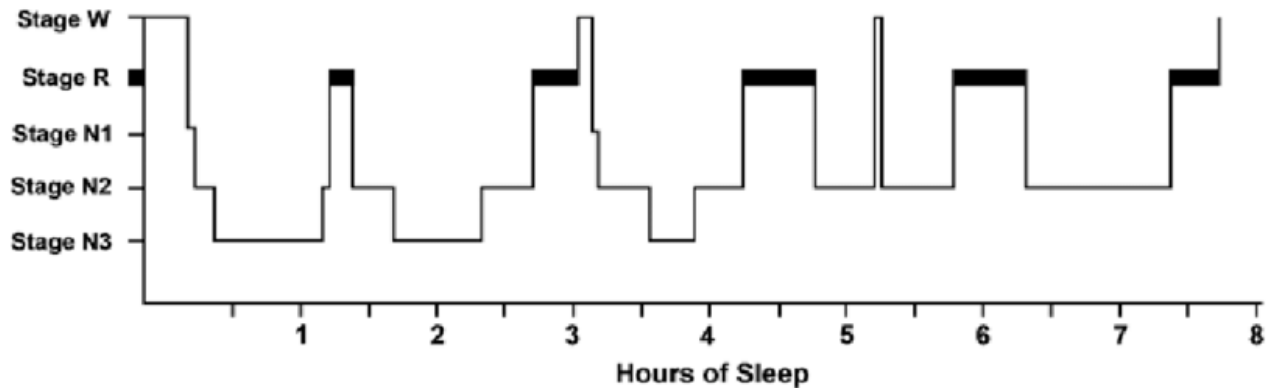


Insomnia in Children with Medical Complexity (CMC)

Sleep cycle



REM: Most dreams occur here, active brain and “paralyzed” body

Stage N1: Transitional sleep

Stage N2: Light sleep

Stage N3: Slow-wave (deep) sleep

- *More N3 sleep earlier in sleep*
- *More REM sleep later in sleep*

Chronic insomnia disorder criteria

- A. Reports of difficulties (1) falling asleep, (2) staying asleep and/or (3) early waking
- B. Daytime consequences of sleep problem
- C. Adequate opportunity for sleeping
- D. Frequent ($\geq 3x/wk$) and chronic ($3 \geq$ months)
- E. Not explained by another sleep/wake disorder, medical condition, or mental health disorder

Epidemiology

- About **85%** of children with NDD meet above criteria (probably similar prevalence in CMC)
- Commonly last into adolescence and adulthood

Causes of insomnia in CMC

1. Biologic:

- Neurochemical/hormonal factors
- Circadian clock factors
- Sensory differences
- Mental health issues (e.g., depression/anxiety)

2. Medical:

- **CNS:** Seizures, delirium, pain/neuro-irritability, spasticity/dystonia
- **Resp:** Sleep-disordered breathing (e.g., OSA), allergies
- **GI:** GERD, constipation, intussusception
- **MSK:** Fractures/dislocation
- **Derm:** Pressure injury, rashes
- **Medications**
- **Technology** (e.g., alarms, enteral feeds overnight)

3. Behavioral:

- Lack of sleep routine
- Screen time
- Lack of exercise
- Maladaptive association
- Limit-setting/sleep-limiting issues
- Parental concerns/stress

Stepwise management approach

1. Evaluation of sleep

- A. History/physical examination, including:
 - ROS – focus on common causes of insomnia in CMC
 - Sleep questionnaires (refer to “BEARS Questionnaire” and “Sleep-Disordered Breathing Questionnaire”)
- B. Sleep diary (refer to “Pediatric Sleep Log”)
- C. Actigraphy
- D. Overnight PSG and video recording of events

2. Address above causes of insomnia, if possible

3. Psychoeducation and behavioral interventions (refer to the “Sleep Hygiene for Children and Teens” document)

4. Melatonin

MoA	Natural sleep/wake regulator
Main indication	Melatonin secretion deficiency secondary to underlying neurological condition, particularly with vision impairment
Uses	<ul style="list-style-type: none"> - Delayed sleep onset (>30 min) - Evidence of benefit for prolonged-release melatonin with problems of sleep maintenance - May provide help with sleep-onset association insomnia
Dose	<ul style="list-style-type: none"> - Infants: 1.5 mg HS - Children: 3 mg HS - Adolescents: 6-10 mg HS - Children with special needs may need doses up to 10 mg HS
Route	PO (can be given via G-tube and J-tube)
Timing	To be given 30-60 min prior to desired bedtime, at same time, every night
Side effects	Nightmares and headaches
Formulations	1, 3, 5, 10 mg tabs and 1 mg/mL liquid

5. Meds

- a. Hyper-excitability (e.g., ASD, ADHD, children with SNI)
 - i. Clonidine
 - ii. Gabapentin – usually not a direct indication
 - iii. Tryptophan
 - iv. Zopiclone
- b. Antipsychotics (e.g., quetiapine) - rarely given for sleep routinely; particularly useful if delirium/behavioral challenges awakening patient and at EoL
- c. Benzo – (e.g., clonazepam) - very rarely given for sleep routinely; particularly useful if seizures/spasticity/dystonia awakening patient and at EoL
- d. Chloral hydrate (never given for sleep routinely)

References:

1. Jan, J.E., & Freeman, R.D. (2004). Melatonin therapy for circadian rhythm sleep disorders in children with multiple disabilities: what have we learned in the last decade? *Developmental Medicine & Child Neurology*. 46(11):776-82.
2. *Pediatric Palliative Care Approach to Pain & Symptom Management*. Dana Farber Cancer Institute/Boston Children's Hospital Pediatric Advanced Care Team. 2020.