To Sleep or Not To Sleep: Sleep problems in individuals with developmental and intellectual disabilities

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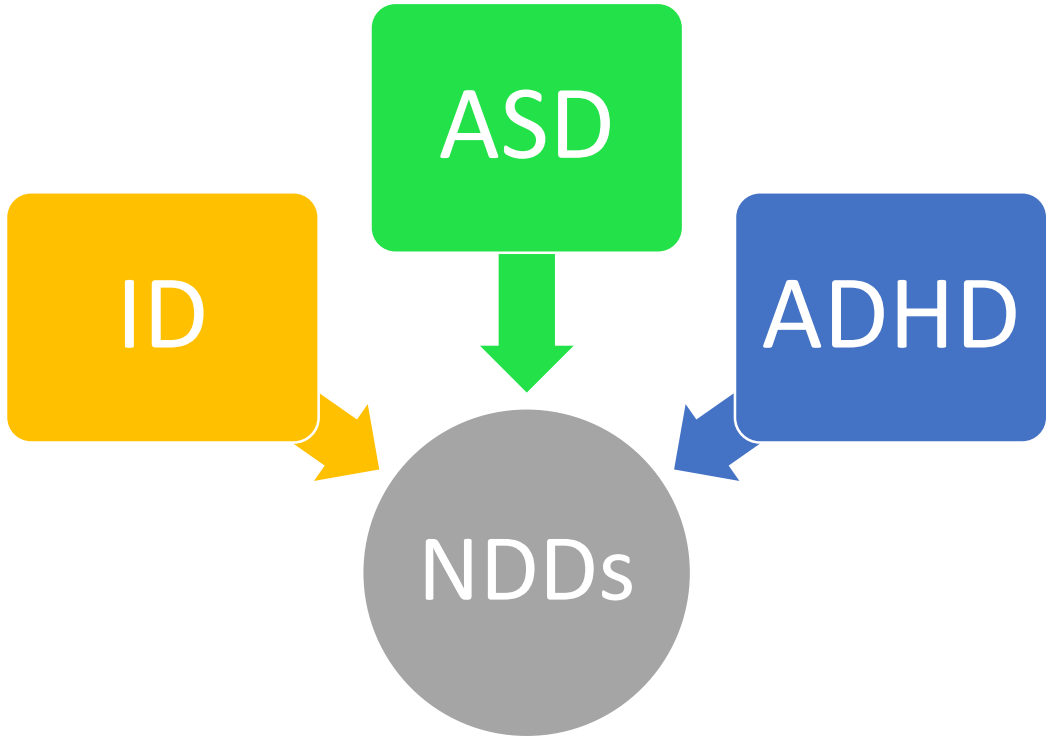
Objectives

- Learn about relationships between sleep and health in this population
  - Why does sleep mater?
- Define “normal sleep”
  - Name the two main processes regulating sleep
  - Be aware of normal sleep durations and patterns across the life span
  - Identify differences in sleep duration and quality in this population
- Name common sleep disorders in this population
  - List common signs and symptoms associated with sleep disorders
  - List risk factors associated with different sleep disorders
  - Learn about screening tools for sleep problems
- Learn about interventions to improve sleep quality

Neurodevelopmental Disorders (NDD)

- NDDs are group of disorders caused by changes in early brain development → cognitive and behavioral changes in motor, sensory, speech and/or language systems.
- NDDs 1-2% of general population.

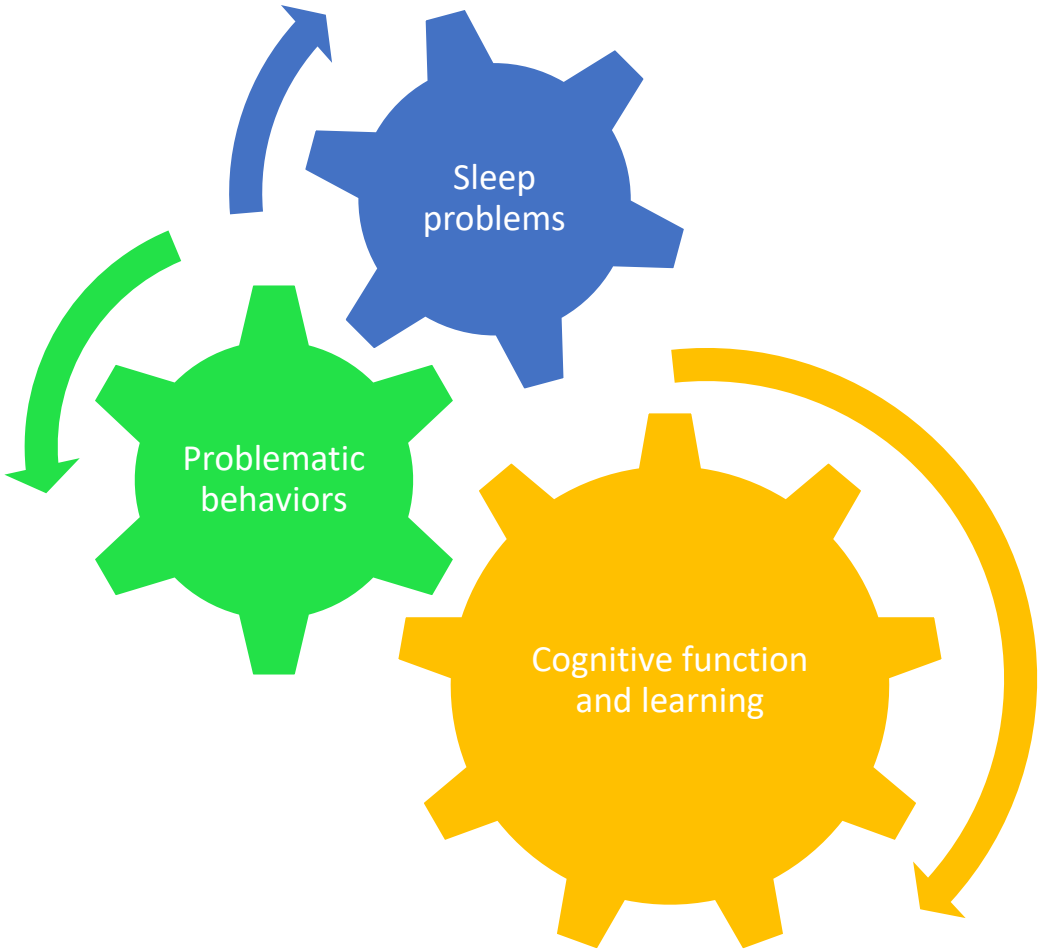


NDDs often associated with intellectual disabilities (IDs), attention deficit/hyperactivity disorder (ADHD) and/or autism spectrum disorder (ASD)

Why Does Sleep Matter?

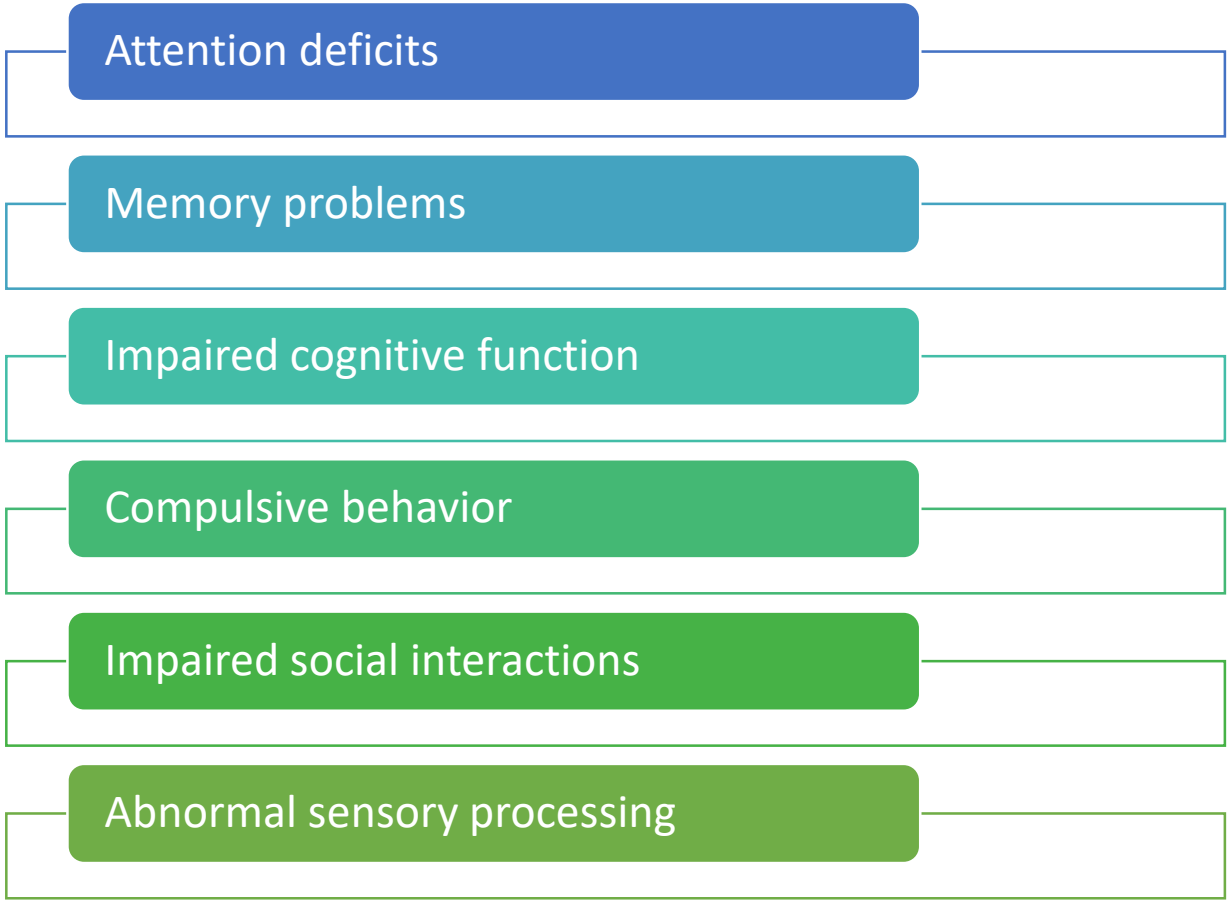
Sleep and Neurodevelopment Disorders Often Are *Poor* Bedfellows

- Sleep problems are common and often persistent in people with NDDs, ID, ADD/ADHD, and/or ASD;
- Complex relationships often bidirectional between sleep problems, problematic behaviors, cognitive function and learning in such individuals.



Deficits Vary in Individuals with Different Disorders

- Sleep (or lack of it) impact upon all of these:



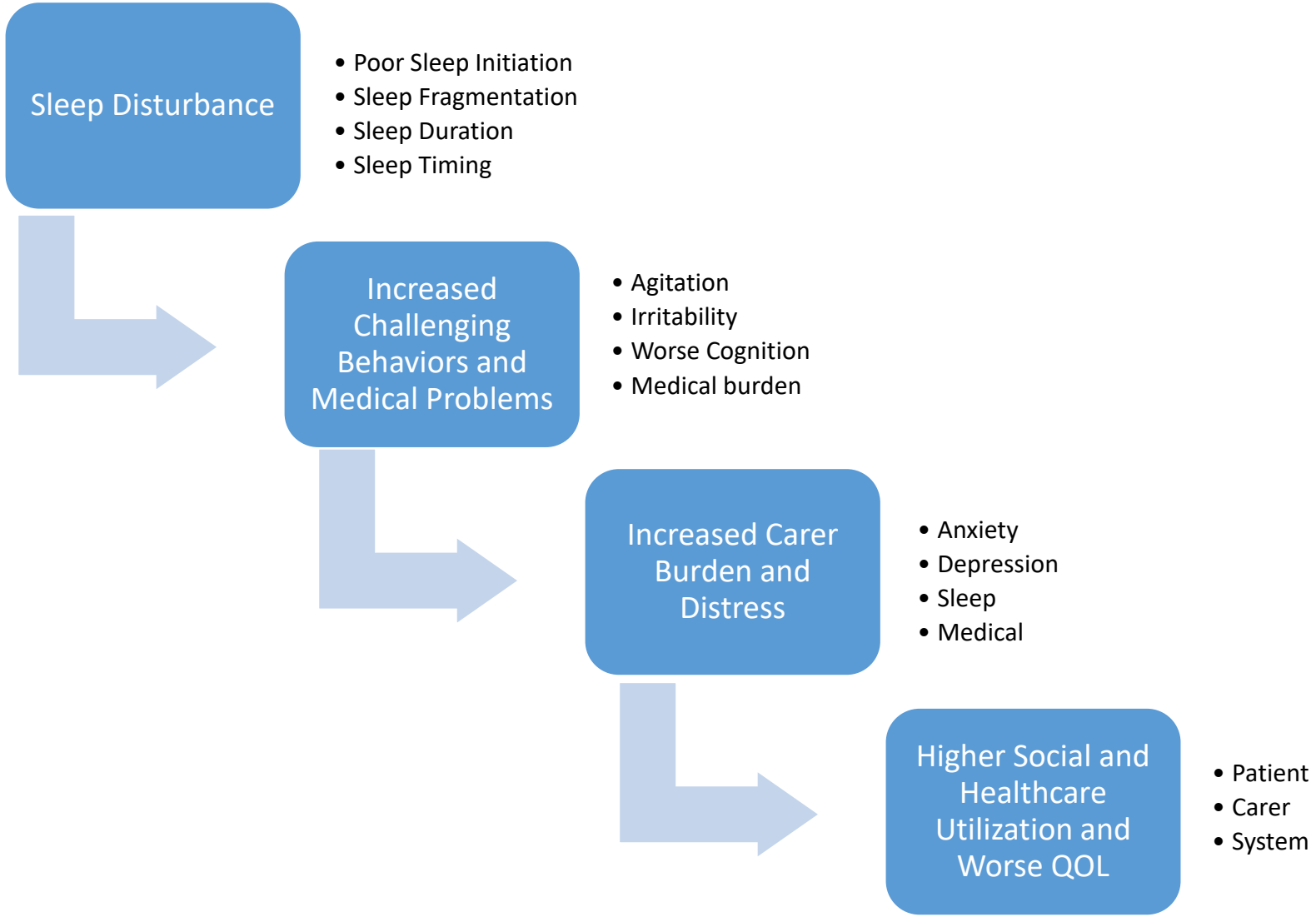
Sleep Disorders in this Population are the Same as Those Seen in Neurotypical People

- Difficulty falling asleep
- Difficulty staying asleep
- Early morning awakenings
- Unrefreshing Sleep
- Daytime sleepiness
- Suspected sleep apnea
- Reversals of sleep/wake timing
- Parasomnias

<u>However</u>, sleep problems in people with NDD/ID compared to general population are:

- More Common
- More Frequent
- More Persistent
- More Severe

A Domino Effect



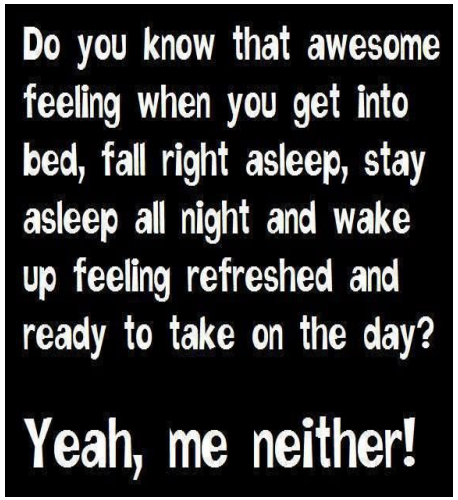
The First Step is to Identify a Problem

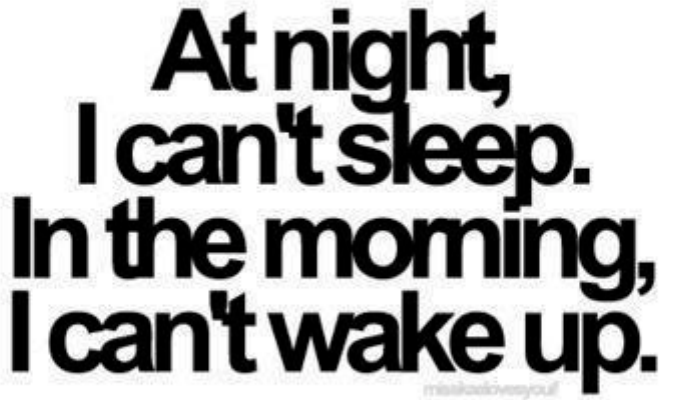
- Sleep is often overlooked
  - Subjective information provided by carers
  - May have differing opinions
  - Sleep disturbance may be accepted as part of the person's condition
  - Sleep Disorders considered difficult to treat

The First Step is to Identify a Problem

- Identify
  - “Do you consider that you have sleep problems?”
  - Ask questions with curiosity
  - Explore what they experience and find most difficult
- Normalize
  - Their experience is valid and important
  - Respond by reflection statements to confirm you understand
- Educate
  - Ask permission to share information
  - Help the patient and/or carer understand the effects of lifestyle and environment on sleep
- Brainstorm
  - Even modest adaptations to daily routine and sleeping environment can be of benefit
  - Interventions need to be tailored to the person and carer

What is “Normal Sleep?”





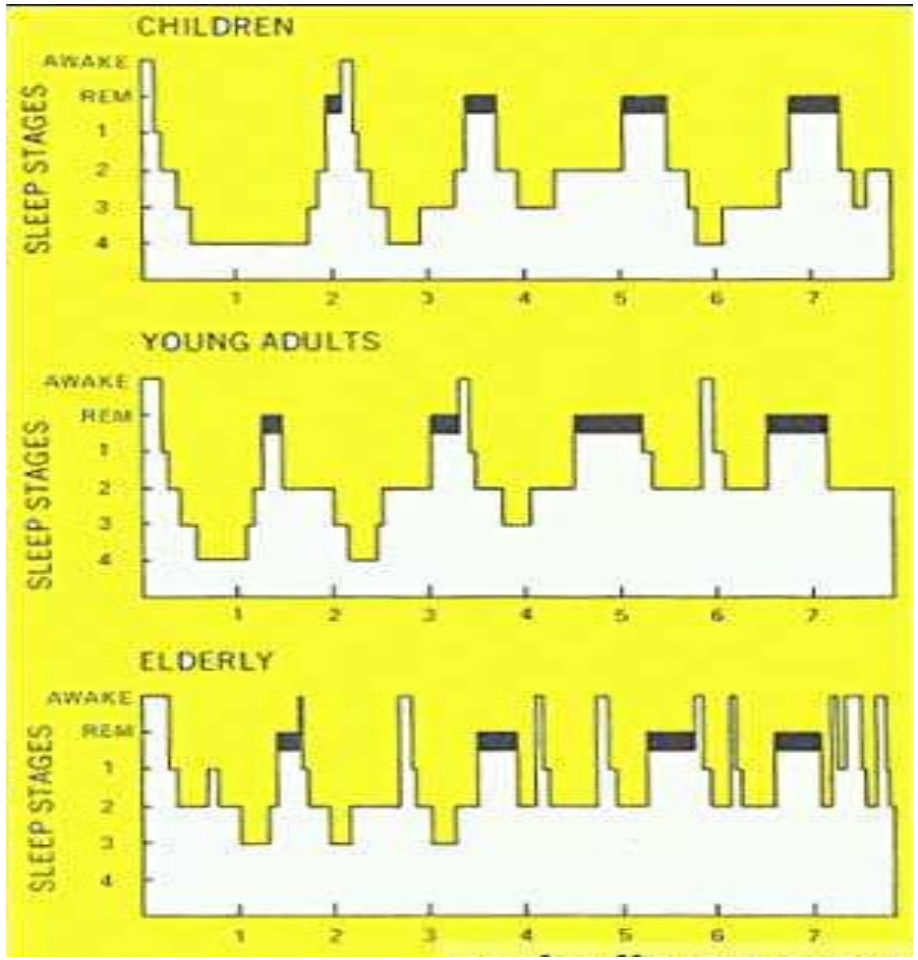
QUANTITY

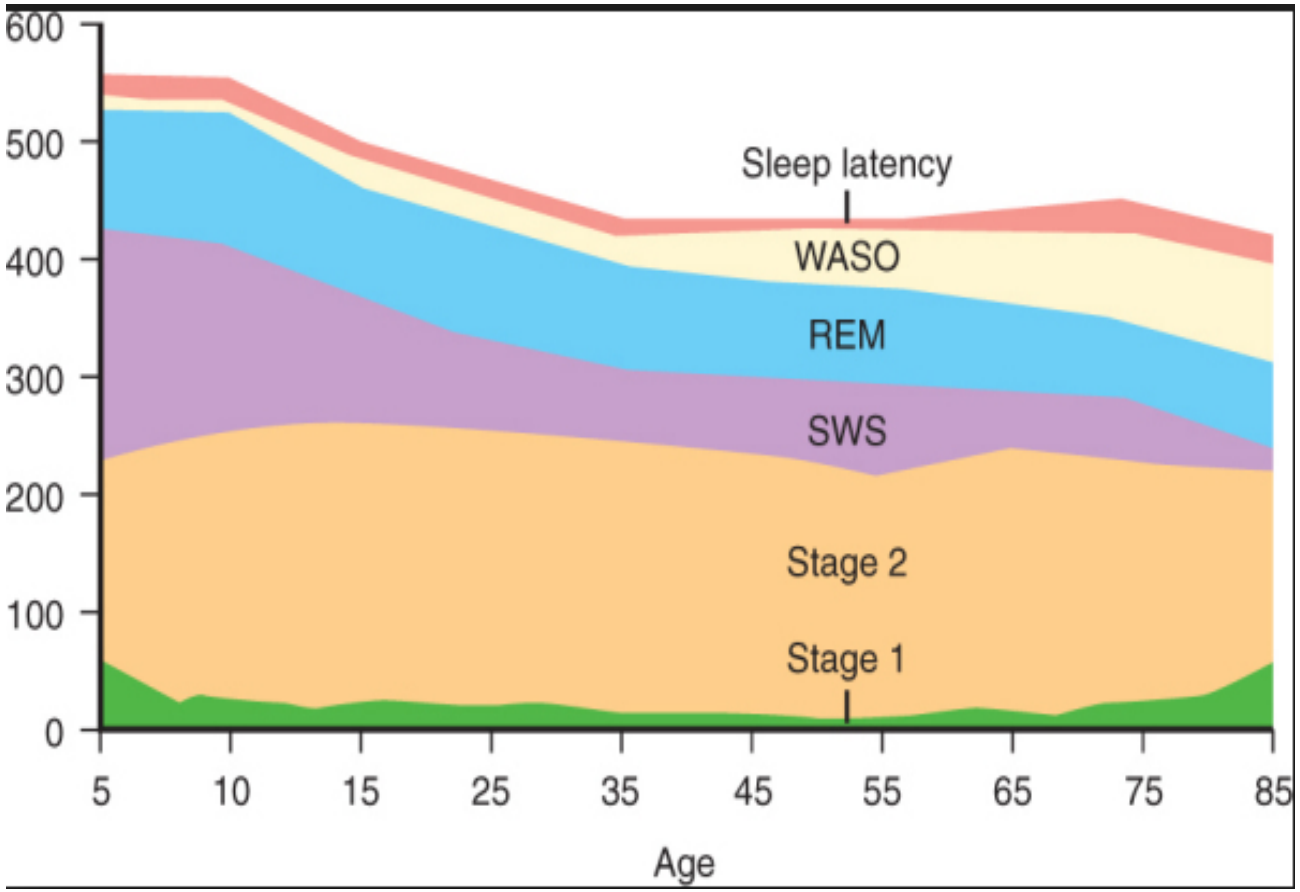
QUALITY

Sleep Needs Across Life Span

AGE	Sleep Hours (per 24 hour period)
Full Term 0-3 months	14-17
4-11 months	12-15
1-2 years	11-14
3-5 years	10-13
6-13 years	9-11
14-17 years	8-10
18-64 years	7-9
≥ 65 years	7-8 +/- naps

Sleep Through the Ages





How Much Sleep is Enough?

- Genetically determined
  - 4-11 hours per 24 hours
  - Average is 7.5-9 hours

Owls and Larks

- Night owls
  - Stay up late
- Morning larks
  - Rise early

What are the two main factors that regulate sleep/wake patterns?

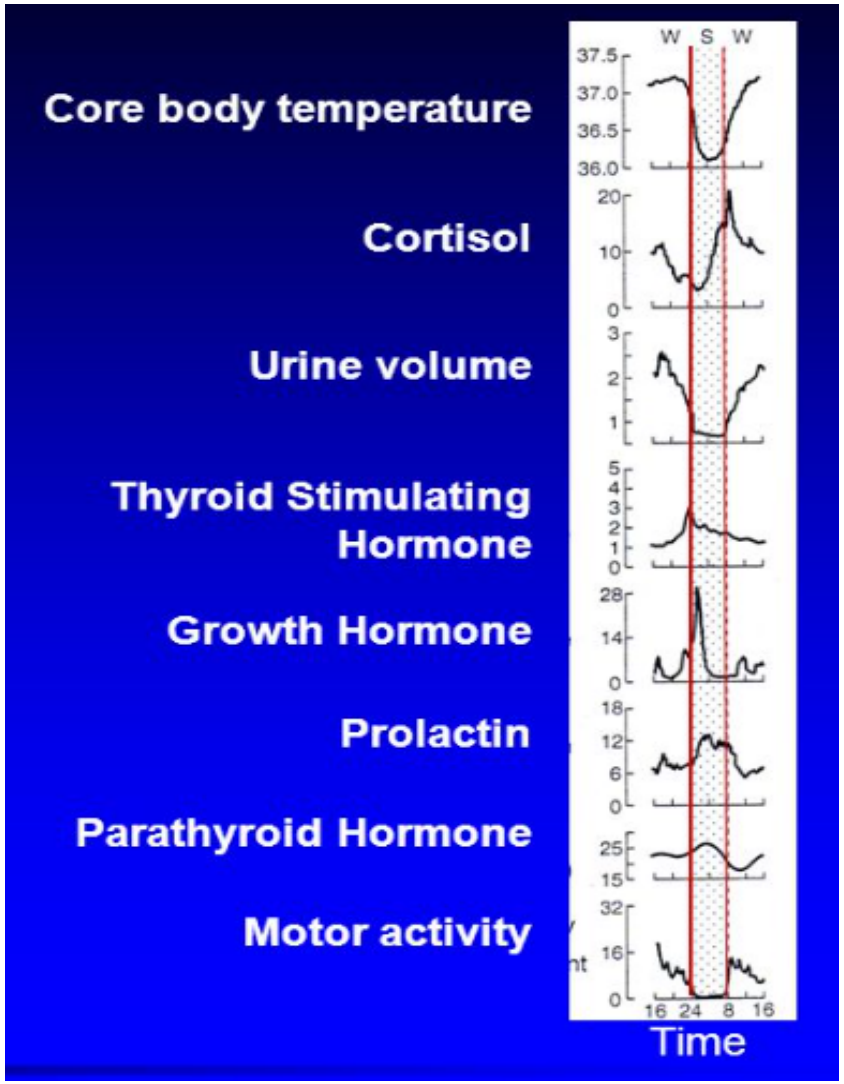
Circadian Rhythm = Process C

Homeostatic sleep drive or “sleep pressure” = Process S

Biologic Clocks Influence All

Multiple Physiologic Variables Demonstrate Endogenous Circadian Rhythms: Each of Our Cells Have Little Clocks

- In each cell there are circadian oscillations
- Generated by negative feedback of proteins upon transcription of the genes that encode them
- At least 10 CLOCK genes (e.g. Bmal1, Clock, Per, Cry)



What is the main factor that helps synchronize the circadian clock on a daily basis?

A) Activity

B) Feeding schedule

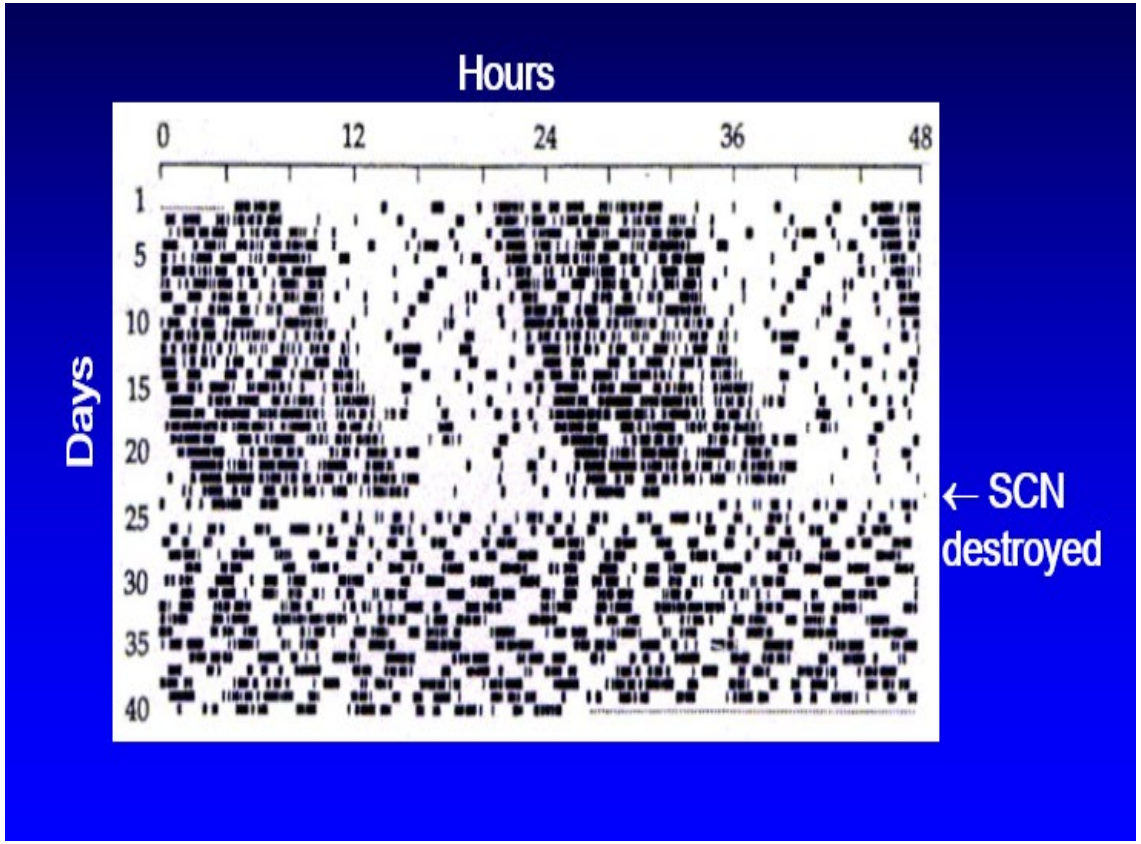
C) Light

D) Orexin

E) Social Cues

Our Clock Needs to Be Reset Daily

- Circadian Rhythm: a near 24 hour oscillation in behavior
  - present in almost all eukaryotic organisms from single celled algae to humans
- Our internal clocks run slightly longer than 24 hours
  - **24.2-24.9 hours**
- SCN uses zeitgebers (time-givers or time cues) to help synchronize (entrain) or reset the clock daily;
- Key zeitgebers:
  - **Light**
  - Feeding Schedules
  - Melatonin
  - Activity



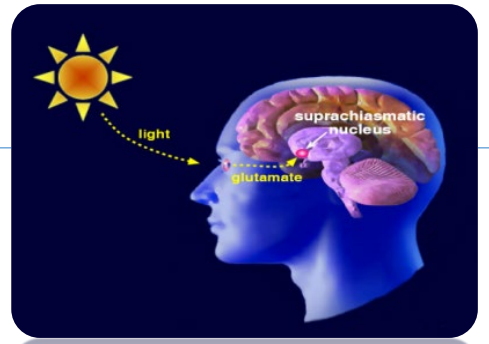
Process for Sleep Cycle

Eyes

No light signal sent to the Suprachiasmatic nucleus

Suprachiasmatic Nucleus (SCN)

Master clock signals other circadian oscillators



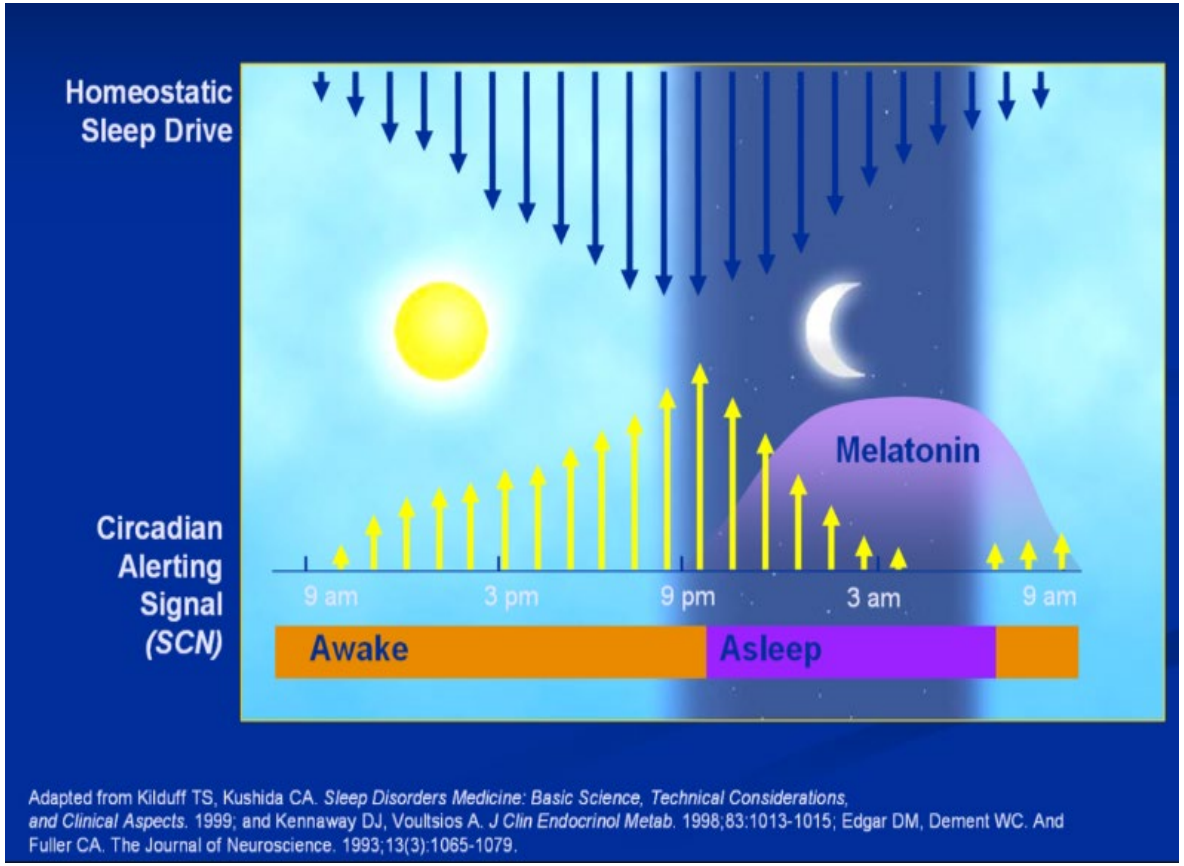
Pineal Gland

Secretes melatonin

Promotes Sleep

Homeostatic Sleep Drive

- AKA “Sleep Pressure”
- Sleep pressure increases the longer we are awake
- Adenosine rises as sleep debt builds up (byproduct of ATP)
  - Inhibits body processes of wakefulness
  - “rinsed out” during sleep



Taking a Sleep History:

- The duration of the symptoms
- Any known trigger?
- Sleep times over 24 hrs and over a week:
  - Bed time and wake times on weekdays and weekends
  - Duration until sleep onset
  - Number, duration, known causes of awakenings
    - Clock Watching?
  - Nap times and lengths
- Sleep environment
  - TV in room? Clocks? Lighting? Noises? Roommates? Night checks? Pets?
  - Room should be quiet, dark, comfortable (cooler) temp, comfortable mattress
- Exposures:
  - Timing and amount of caffeine, nicotine, exercise, electronic device use, work
- Assessment of any symptoms of disturbed sleep

Case: A 22-year-old male presents with his mother to the clinic reporting that he has had worsening insomnia and irritability.

Lets take some history- what could we ask?

When did the symptoms start?

He had his eyes removed at age 14 due to bilateral retino-blastoma.

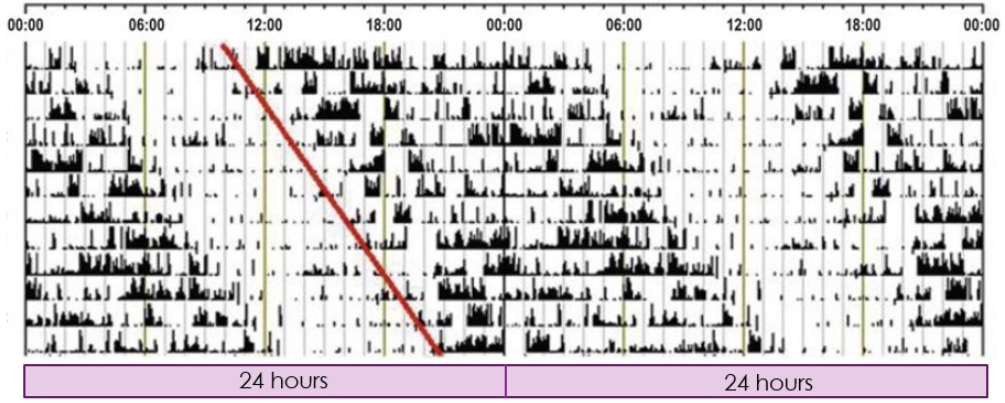
Can you describe his usual sleep and wake schedule?

They have a hard time identifying his “usual” sleep and wake times, stating “they are all over the place.”

She has noticed that there are weeks that he has a harder time interacting with others in the day due to sleepiness, then has difficulty going to sleep.

What evaluation could we do to help identify his sleep patterns?

Overnight actigraphy for 1 month shows that his sleep onset seems to march in a stair-step pattern.



Instruments We Use to Study Sleep Disorders in People with NDD

- Sleep questionnaires
- Sleep diary
- Actigraphy
- In-lab Polysomnography
- Home Sleep Apnea Test

Name_____ Date_____

Sleep Quality Assessment (PSQI)

What is PSQI, and what is it measuring?

The Pittsburgh Sleep Quality Index (PSQI) is an effective instrument used to measure the quality and patterns of sleep in adults. It differentiates "poor" from "good" sleep quality by measuring seven areas (components): subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications, and daytime dysfunction over the last month.

INSTRUCTIONS:

The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

During the past month,

1. When have you usually gone to bed? _____
2. How long (in minutes) has it taken you to fall asleep each night? _____
3. What time have you usually gotten up in the morning? _____
4. A. How many hours of actual sleep did you get at night? _____
   B. How many hours were you in bed? _____

5. During the past month, how often have you had trouble sleeping because you	Not during the past month (0)	Less than once a week (1)	Once or twice a week (2)	Three or more times a week (3)
A. Cannot get to sleep within 30 minutes				
B. Wake up in the middle of the night or early morning				
C. Have to get up to use the bathroom				
D. Cannot breathe comfortably				
E. Cough or snore loudly				
F. Feel too cold				
G. Feel too hot				
H. Have bad dreams				
I. Have pain				
J. Other reason (s), please describe, including how often you have had trouble sleeping because of this reason (s):				
6. During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep?				
7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?				
8. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done?				
9. During the past month, how would you rate your sleep quality overall?	Very good (0)	Fairly good (1)	Fairly bad (2)	Very bad (3)

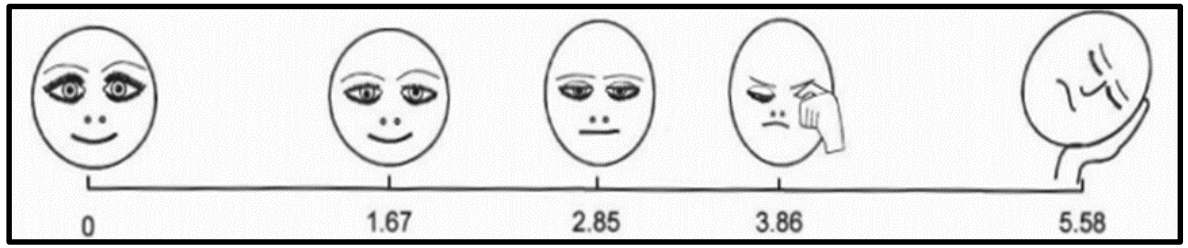
Scoring

Component 1	#9 Score	C1 _____
Component 2	#2 Score (<15min (0), 16-30min (1), 31-60 min (2), >60min (3)) + #5a Score (if sum is equal 0=0; 1-2=1; 3-4=2; 5-6=3)	C2 _____
Component 3	#4 Score (>7(0), 6-7 (1), 5-6 (2), <5 (3)	C3 _____
Component 4	(total # of hours asleep) / (total # of hours in bed) x 100 >85%=0, 75%-84%=!, 65%-74%=2, <65%=3	C4 _____
Component 5	# sum of scores 5b to 5j (0=0; 1-9=1; 10-18=2; 19-27=3)	C5 _____
Component 6	#6 Score	C6 _____
Component 7	#7 Score + #8 score (0=0; 1-2=1; 3-4=2; 5-6=3)	C7 _____

Add the seven component scores together _____ *Global PSQI* _____

A total score of "5" or greater is indicative of poor sleep quality.
If you scored "5" or more it is suggested that you discuss your sleep habits with a healthcare provider

Self-Reported Sleepiness Scales



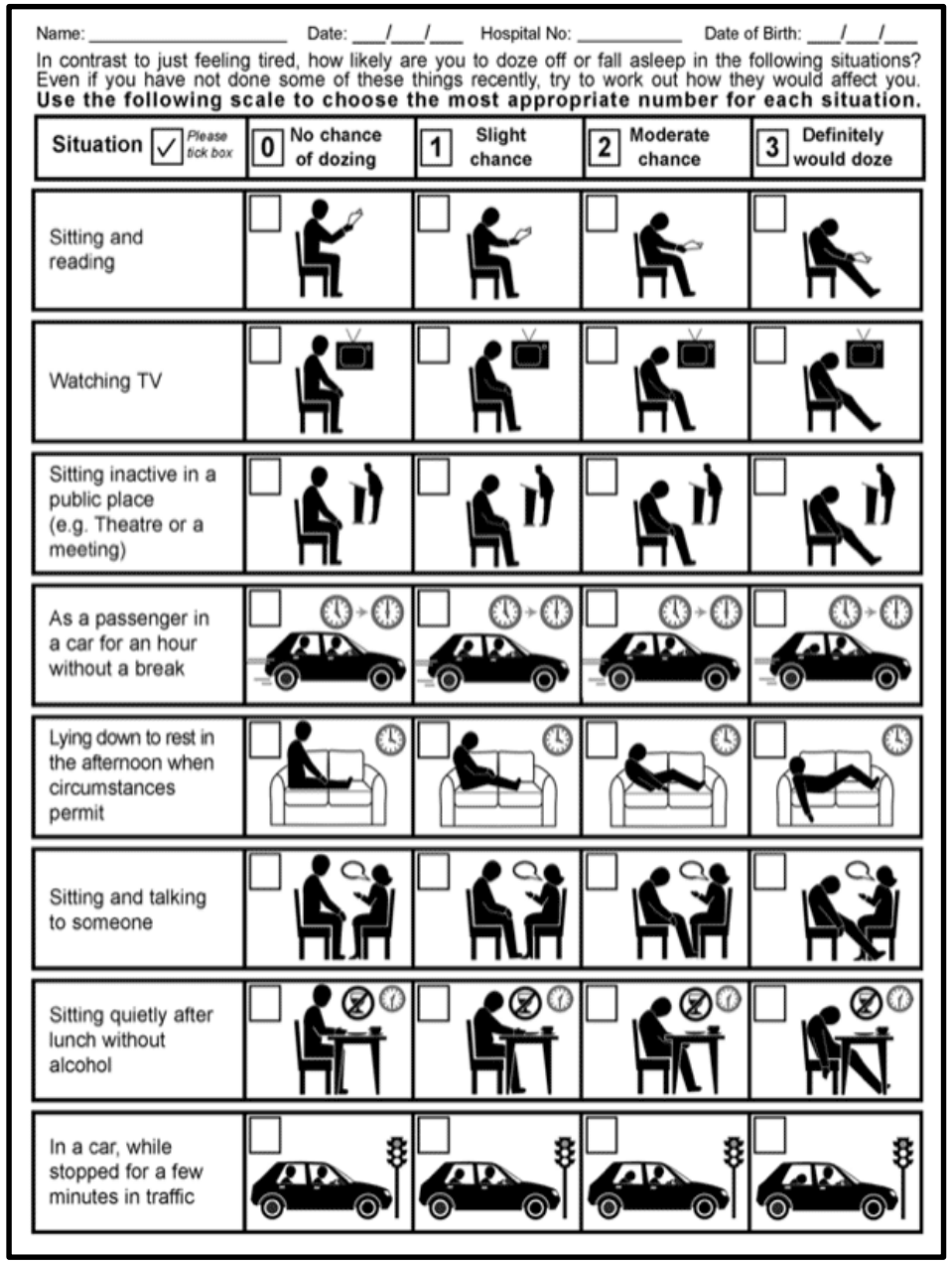
Epworth Sleepiness Scale

How likely are you to doze off or fall asleep in the following situations?
Answer considering how you have felt over the past week or so.

0 = Would never doze
1 = Slight chance of dozing
2 = Moderate chance of dozing
3 = High chance of dozing

1. Sitting and reading
2. Watching TV
3. Sitting inactive in a public place (e.g., theater or meeting)
4. As a passenger in a car for an hour without a break
5. Lying down to rest in the afternoon when able
6. Sitting and talking to someone
7. Sitting quietly after a lunch without alcohol
8. In a car while stopped for a few minutes in traffic

Abnormal ESS score >10.



Maldonado et al. Pictorial sleepiness scale based on cartoon faces. Sleep 2014;27(3):544.

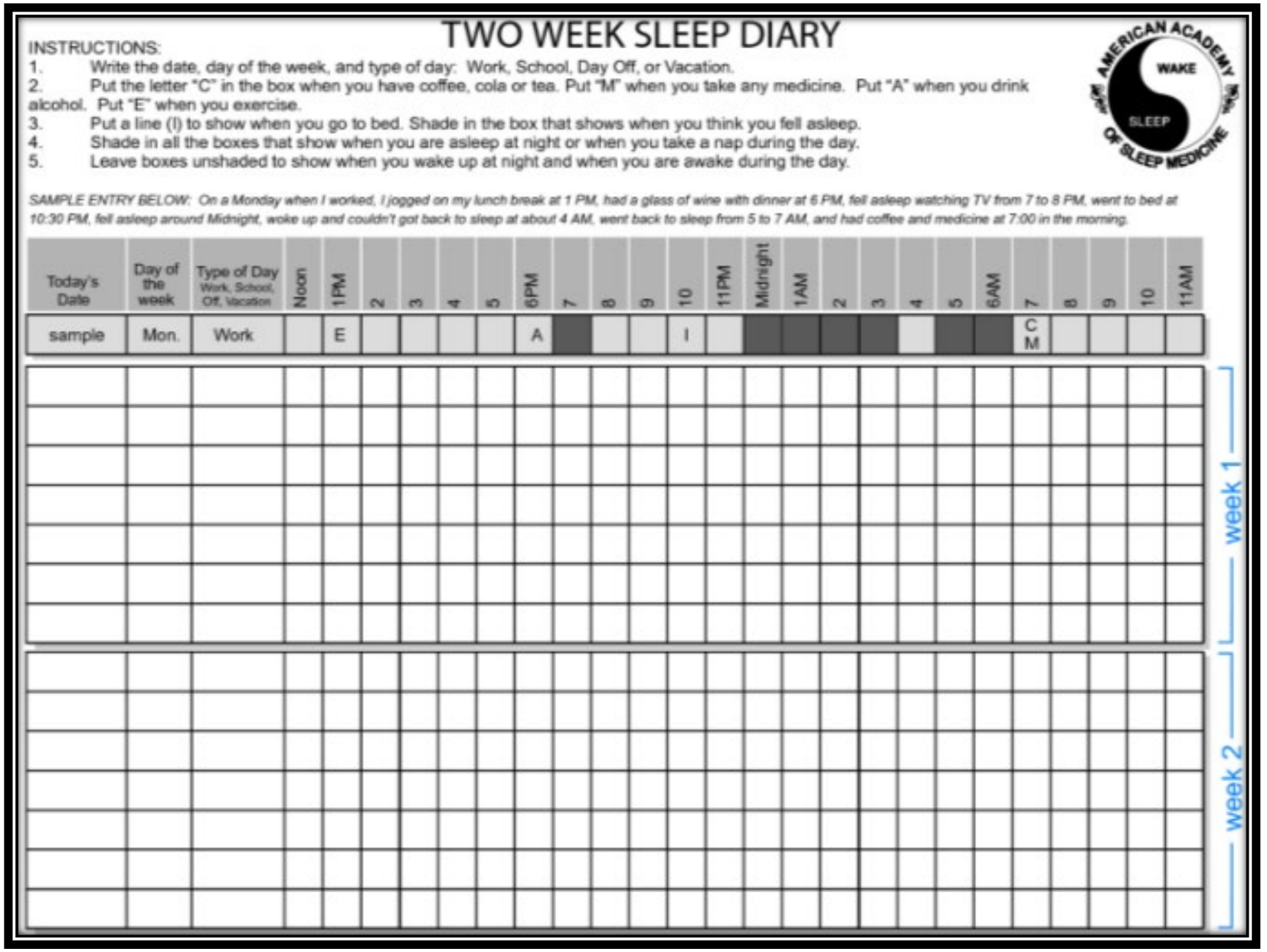
Sleep Diary

It is virtually impossible to treat insomnia or circadian rhythm diary without a sleep diary;

Actigraphy can help but still need a diary;

Inability to complete a diary can be a measure of willingness to pursue treatment

Can use sleep apps



TWO WEEK SLEEP DIARY

INSTRUCTIONS:

1. Write the date, day of the week, and type of day: Work, School, Day Off, or Vacation.
2. Put the letter "C" in the box when you have coffee, cola or tea. Put "M" when you take any medicine. Put "A" when you drink alcohol. Put "E" when you exercise.
3. Put a line (|) to show when you go to bed. Shade in the box that shows when you think you fell asleep.
4. Shade in all the boxes that show when you are asleep at night or when you take a nap during the day.
5. Leave boxes unshaded to show when you wake up at night and when you are awake during the day.

AMERICAN ACADEMY OF SLEEP MEDICINE — WAKE / SLEEP

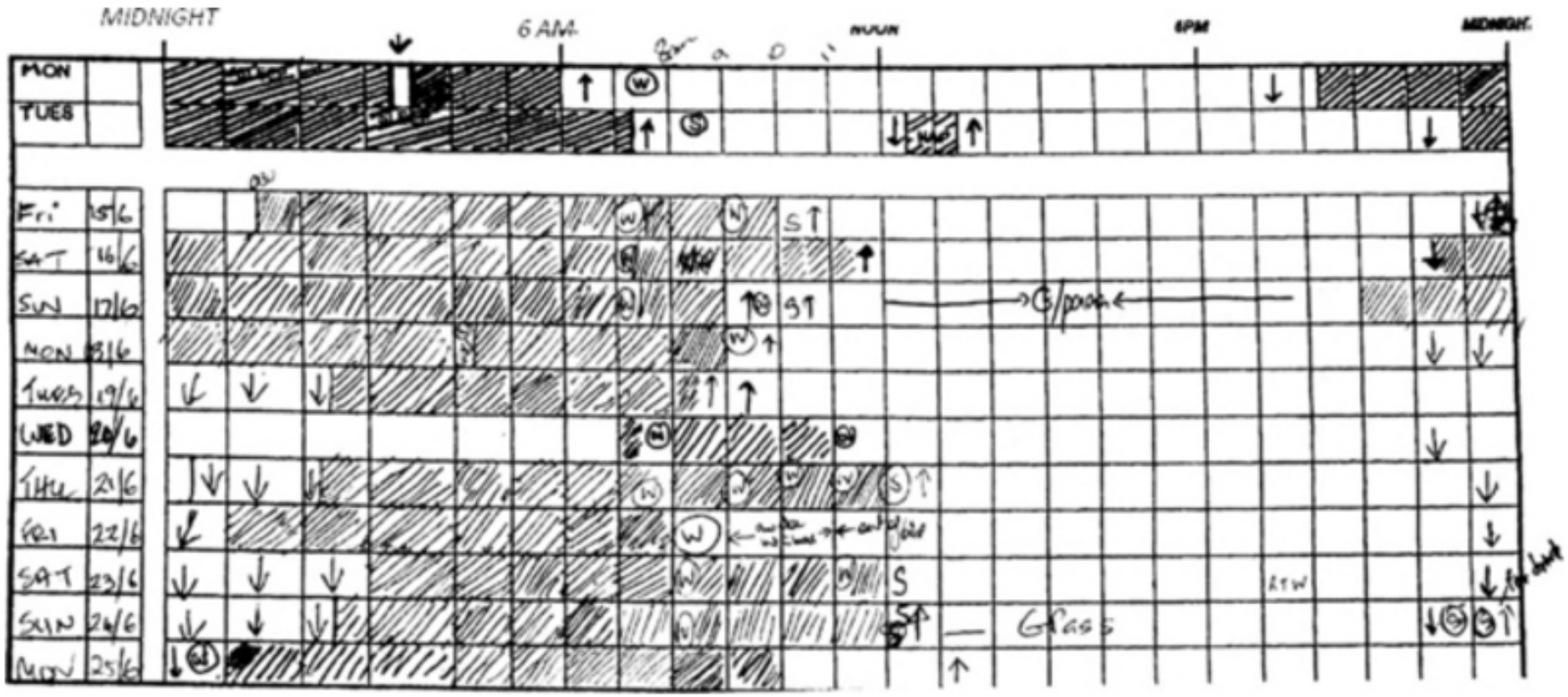
SAMPLE ENTRY BELOW: On a Monday when I worked, I jogged on my lunch break at 1 PM, had a glass of wine with dinner at 6 PM, fell asleep watching TV from 7 to 8 PM, went to bed at 10:30 PM, fell asleep around Midnight, woke up and couldn't got back to sleep at about 4 AM, went back to sleep from 5 to 7 AM, and had coffee and medicine at 7:00 in the morning.

Today's Date	Day of the week	Type of Day (Work, School, Off, Vacation)	Noon	1PM	2	3	4	5	6PM	7	8	9	10	11PM	Midnight	1AM	2	3	4	5	6AM	7	8	9	10	11AM
sample	Mon.	Work		E					A				I									C M				

week 1

week 2

Sleep Diary Late Bed and Wake Times



- Obstructive sleep apnea (OSA) is probably only sleep disorder in which a sleep diary not so helpful.

Most Common Sleep Problems in people with NDD, ID and/or ASD

- Difficulty falling and/or staying asleep;
- Frequent nocturnal awakenings;
- Early morning awakenings;
- Too much time in bed not sleeping;
- Long daytime naps; day/night reversal;
- Impairments in daytime arousal and vigilance;
- Meltdowns and behavior problems exacerbated by insufficient sleep/sleepiness;
- Impaired circadian (biologic) clock rhythms.

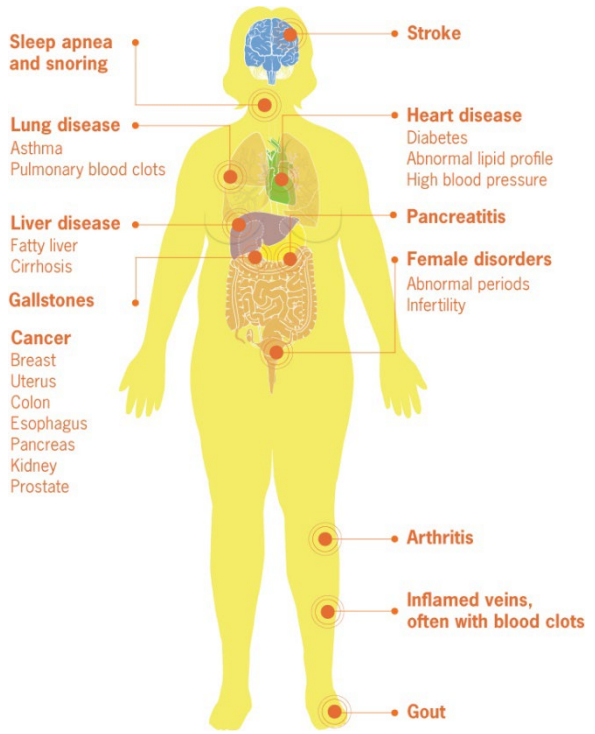
Factors Which Can Contribute to Sleep Problems in people with NDD and/or ID

Intrinsic abnormalities of sleep regulation	• Melatonin, growth hormone, oxytocin, ferritin, clock gene mutations, hypothalamic dysfunction, central hypersomnias
Comorbid medical conditions	• Epilepsy, pain, asthma, eczema, GERD, sensory deficits, physical deformities, developmental delay, learning disabilities, communication difficulties
Psychiatric comorbidities	• Anxiety, depression, PTSD, hallucinations, psychosis
Medication effects	• Stimulants, sedatives, antipsychotics, antidepressant, antiepileptics
Primary sleep disorders	• Sleep apnea, hypoventilation, hypoxemia, RLS, parasomnias, insomnia, circadian rhythm disorders

Contributors to Sleep Problems

Medical illnesses

- Obesity
  - Airway Obstruction
  - Diminished Breathing Effort
- Cardiac Disease
  - Arrhythmias
  - Central Sleep Apnea
- Pulmonary disease
  - Hypoxemia
  - Hypercarbia
- Diabetes Mellitus
  - Energy Metabolism
- Kidney Disease
  - Fluid Balance
- Pain
  - Hyperarousal
  - Restlessness
- Seizures
  - Hyperarousal



Contributors to Sleep Problems

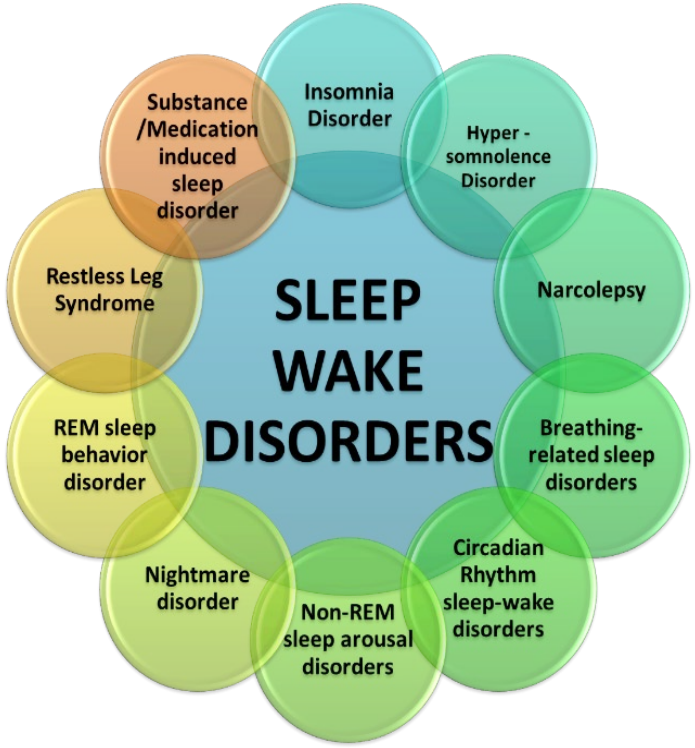
- Psychiatric and Behavioral factors
  - Anxiety
  - Depression
  - Obsessive Compulsive Behaviors
  - Cognitive Problems
  - Caregiver Interactions

Contributors to Sleep Problems

- Medications
  - Sedating Medications
    - Anti-seizure medications
    - Hypertension medications
    - Muscle relaxants
    - Sleep aids
  - Stimulant Medications
    - Stimulants
    - Modafinil
    - Caffeine
    - Antidepressants
  - Psychotropic Medications
    - Antipsychotics
    - Antidepressants
    - Anti-anxiety medications

Common Sleep Disorders in People with NDD/ID

- Insomnia
- Obstructive Sleep Apnea
- Circadian Rhythm Disorders
- Hypersomnia
- Parasomnias
- Sleep Related Movement Disorders



Developmentally Delayed Populations at High Risk for Sleep Disorders

- Down Syndrome
  - Obstructive Sleep Apnea- incidence of 50-100%
  - Insomnia
- Prader Willi
  - Obstructive Sleep Apnea
  - Central Hypersomnia
  - Nocturnal Eating
- Myotonic Dystrophy
  - Obstructive Sleep Apnea
  - Central Sleep Apnea
  - Central Hypersomnia
- Smith Magenis Syndrome
  - Circadian Rhythm Disorders
  - Insomnia
  - Obstructive Sleep Apnea

Developmentally Delayed Populations at High Risk for Sleep Disorders

- Syndromes with Dysmorphic Faces
  - Obstructive Sleep Apnea
- Autism Spectrum
  - Insomnia
  - Sleep related rhythmic movement disorders
- Individuals with Blindness
  - Circadian Rhythm Disorders
- Syndromes with Epilepsy
  - Obstructive sleep apnea
  - Hypersomnia
  - Parasomnias

Some NDDs Have Sleep Problems So Prevalent To Be Considered Behavioral Phenotype

Autistic Spectrum Disorder

Smith-Magenis Syndrome

Rett Syndrome

Down Syndrome

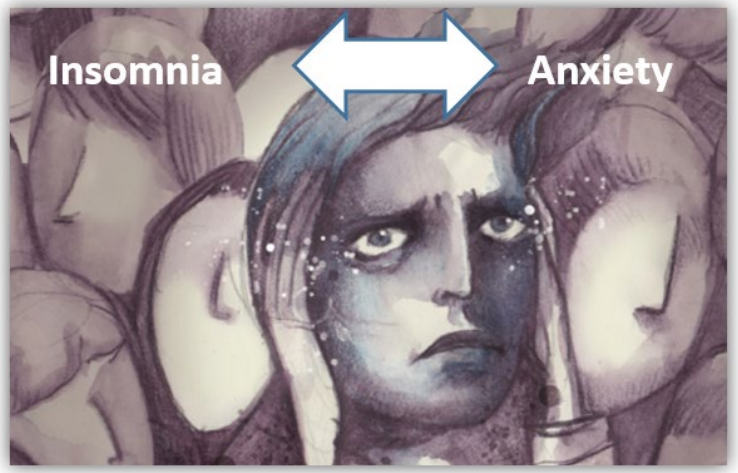
Williams Syndrome

Fragile X Syndrome

Prader-Willi Syndrome

Objective Studies Find Poorer Sleep Architecture in ASD than NT Adults

- ↑ Time to fall asleep
- ↓ Sleep efficiency
- ↑ Fragmented sleep
- ↑ Wake After Sleep Onset (WASO)



1) High insomnia scores correlated with high anxiety scores (not depression);
2) High anxiety scores correlated with hyperactivity (not inattention);
3) Anxiety scores higher in ASD.

McAlonan Grainne Evaluation Of Sleep In Adults With Neurodevelopmental Disorders, Presented September 2016

Smith-Magenis Syndrome (SMS)

Fig. 1 Typical SMS phenotype with 'tented' upper lip and depressed nasal bridge **a**, **b**, **c**, **d**, brachydactyly **a**, **b**. Young adults SMS often present with synophris (**d**, **e**) and prognatism **d**. Wounds from skin picking can be seen at any age **d**

Poisson *et al. Orphanet Journal of Rare Diseases* (2015) 10:111
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ORPHANET JOURNAL OF RARE DISEASES

POSITION STATEMENT Open Access

Behavioral disturbance and treatment strategies in Smith-Magenis syndrome

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Abstract

Background: Smith-Magenis syndrome is a complex neurodevelopmental disorder that includes intellectual deficiency, speech delay, behavioral disturbance and typical sleep disorders. Ninety percent of the cases are due to a 17p11.2 deletion encompassing the *RAI1* gene; other cases are linked to mutations of the same gene. Behavioral disorders often include outbursts, attention deficit/hyperactivity disorders, self-injury with onychotillomania and polyembolokoilamania (insertion of objects into body orifices), etc. Interestingly, the stronger the speech delay and sleep disorders, the more severe the behavioral issues. Sleep disturbances associate excessive daytime sleepiness with nighttime agitation. They are underpinned by an inversion of the melatonin secretion cycle. However, the combined intake of beta-blockers in the morning and melatonin in the evening may radically alleviate the circadian rhythm problems.

Discussion: Once sleep disorders are treated, the next challenge is finding an effective treatment for the remaining behavioral problems. Unfortunately, there is a lack of objective guidelines. A comprehensive evaluation of such disorders should include sleep disorders, potential causes of pain, neurocognitive level and environment (i.e. family and school). In any case, efforts should focus on improving communication skills, identifying and treating attention deficit/hyperactivity, aggressiveness and anxiety.

Summary: Treatment of Smith-Magenis syndrome is complex and requires a multidisciplinary team including, among others, geneticists, psychiatrists, neuropediatricians/neurologists, somnologists, developmental and behavioral pediatricians, and speech and language therapists.

Smith-Magenis Syndrome (SMS)

- Characterized by developmental delay with IQ 40s to 60s, short stature, hoarse deep voice, obesity, scoliosis, distinctive facies and peripheral neuropathy;
- SMS mutation or small interstitial deletion in a crucial transcriptional regulator gene of circadian clock on chromosome 17;
- Circadian rhythm disorders in SMS thought related to disturbed regulation of downstream circadian clock genes;
- 96% of SMS children have inverted endogenous melatonin secretion, peaking in day rather than night;
- Oral acebutolol (b1-adrenergic antagonist, 10 mg/kg) given in morning coupled with evening dose of melatonin improved sleep/wake complaints.
- Cognitive behavior insomnia treatments also needed.
- Screen for symptoms of OSA given midface hypoplasia, obesity and scoliosis.

Rett Syndrome

X-linked Dominant Disorder Affecting Females

- Sleep disturbances part of diagnostic criteria for Rett syndrome (reported >80%);
- Problematic nocturnal behaviors (n= 202):
  - Nocturnal laughter (59%); bruxism (55%); long spells of screaming or inconsolable crying (36%); nocturnal seizures (26%); sleep terrors (18%); sleep talking (18%);
  - Frequent nocturnal awakenings decreased from 54% before age 7 to 40% at age 18;
  - Nocturnal screaming decreased to 30% over age 18;
- Treatment not associated with improvement in sleep problems.

The trajectories of sleep disturbances in Rett syndrome

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Keywords
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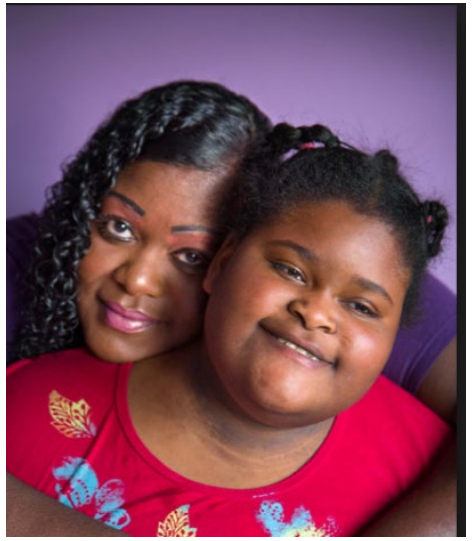
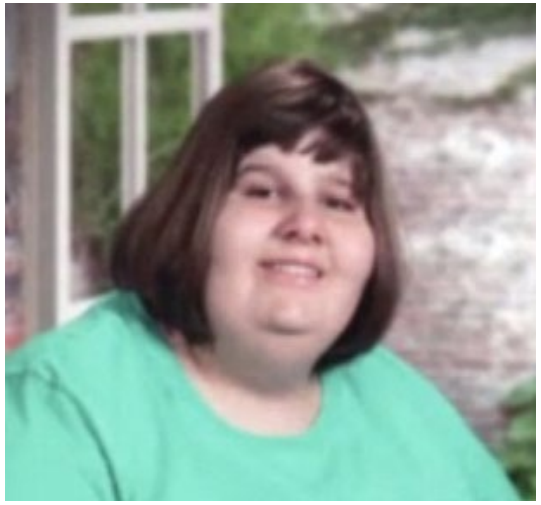
SUMMARY
Rett syndrome is a rare neurodevelopmental disorder usually affecting females, and is associated with a mutation in the *MECP2* gene. Sleep problems occur commonly and we investigated the trajectories and influences of age, mutation and treatments. Data were collected at six time points over 12 years from 320 families registered with the Australian Rett Syndrome Database. Regression analysis was used to investigate relationships between sleep disturbances, age, mutation type and use of treatment, and latent class growth analysis was performed to identify sleep problem phenotypes and model the effect of mutation type. The age range of subjects was 2.0–35.8 years. The study showed that sleep problems occurred in more than 80% of individuals and the prevalence decreased with age. Night laughing and night screaming occurred in 77 and 49%, respectively, when younger. Those with a large deletion had a higher prevalence of night laughing, which often occurred frequently. Treatment was associated with a 1.7% reduction in risk of further sleep problems. High and low baseline prevalence groups were identified. Approximately three-quarters of girls and women with sleep disturbances were in the high baseline group and problems persisted into adulthood. Conversely, 57% with night laughing and 42% with night screaming in the high baseline group exhibited mild improvement over time. Mutation type was not found to be a significant predictor of group membership. In conclusion, the evolution of sleep problems differed between subgroups of girls and women with Rett syndrome, in part explained by age and genotype. Treatment was not associated with improvement in sleep problems.

2014 study found night laughing and night crying more likely to persist in women with large MECP2 gene deletions.

People with Prader-Willi Syndrome (PWS) Often Have Sleep Disordered Breathing but Also Central Hypersomnia





- Severe central hypotonia at birth with a poor suck, weak cry, lethargy, and decreased movement during infancy
- Delayed language development
- Delayed motor milestones
- Characteristic facies (almond-shaped eyes, strabismus, narrow bifrontal diameter, thin upper lip, down-turned mouth)
- Small hands and feet
- Short stature
- Hyperphagia and insatiable appetite by age of 1 to 6 years, morbid obesity by age of 4 years
- Fat storage in the abdomen, buttocks, and thighs even in nonobese patient
- Hypothalamic hypogonadism (genital hypoplasia, incomplete pubertal development, and, in most cases, infertility)
- Stubbornness, temper tantrums, self-injury, skin-picking, food foraging, impulsivity, mood lability, repetitive speech
- Learning difficulties, poor academic performance, mean IQ 60s to 70s
- Impaired social cognition, literal-mindedness, cognitive inflexibility
- Sleep-disordered breathing (especially sleep-related hypoventilation, often mild obstructive sleep apnea)
- Hypothalamic dysfunction with central hypersomnia
- Impaired growth hormone secretion and low serum insulin-like growth factor-I levels

Common Sleep Problems in Developmentally Delayed Individuals

- **Insomnia**
- Obstructive Sleep Apnea
- Circadian Rhythm Disorders
- Hypersomnia
- Parasomnias
- Sleep Related Movement Disorders

Insomnia

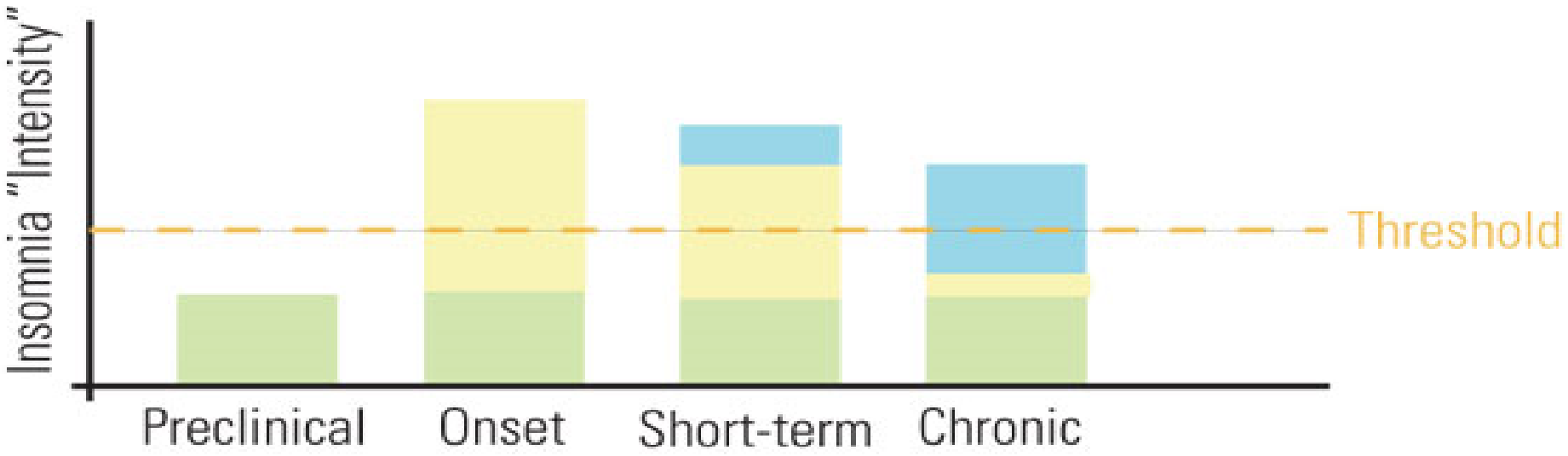
- Hard to sleep
  - Difficulty going to sleep
  - Difficulty staying asleep
  - Waking up too early
  - Poor quality sleep
- Have adequate sleep opportunity
- > 3 nights per week

Speilman's 3 Factor Model of Insomnia

Predisposing Factors
- Biologic traits
- Psychological traits
- Social factors

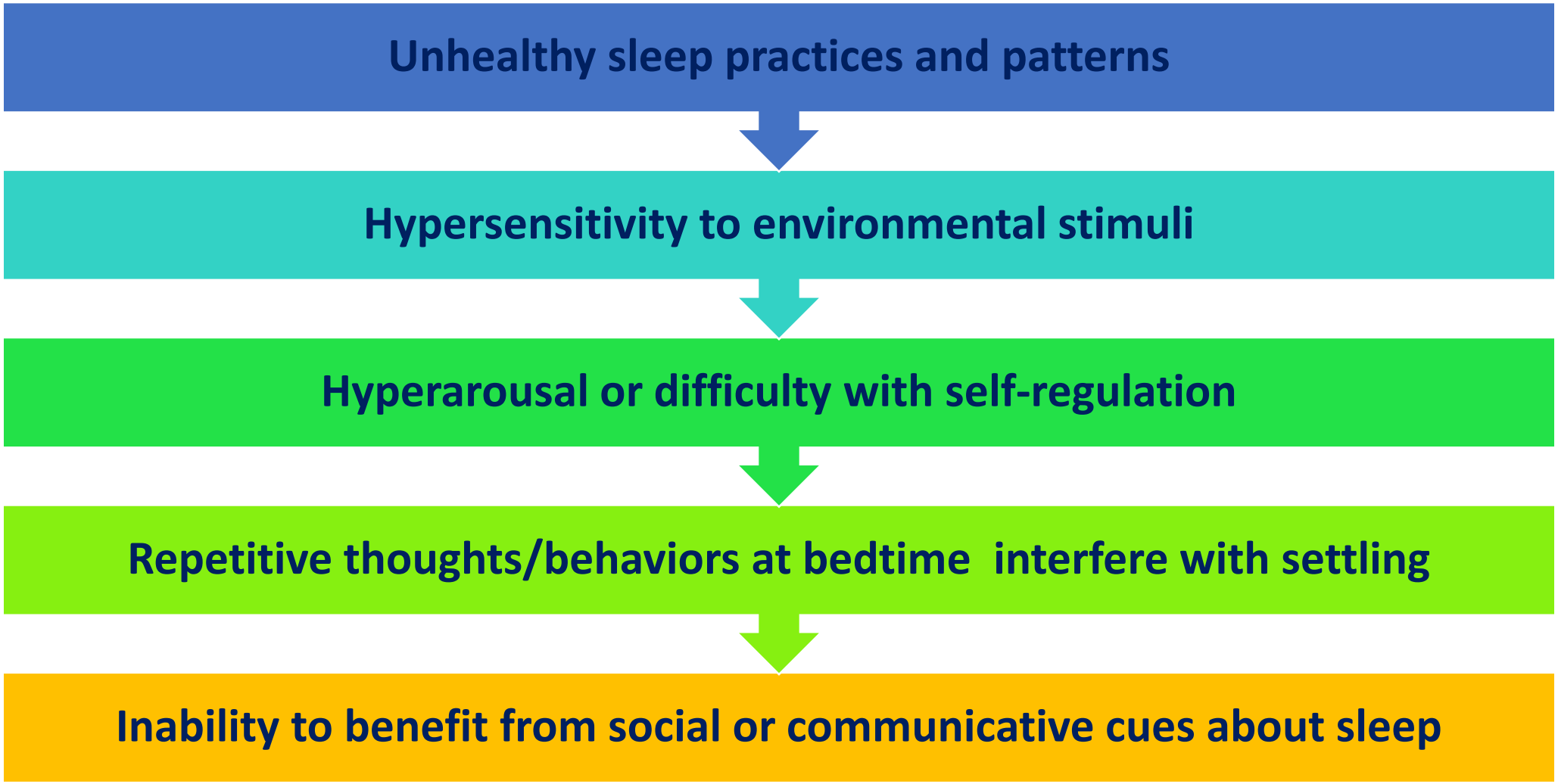
Precipitating Factors
- Medical illness
- Psychiatric illness
- Stressful life events

Perpetuating Factors
- Excessive time in bed
- Napping
- Conditioning



Erman MK. *Primary Psychiatry*. Vol 14, No 7. 2007.

Neurobehavioral Factors Which Can Contribute to Insomnia



Insomnia or…

- Other sleep disorders:
  - Obstructive sleep apnea
  - Restless leg syndrome
  - Periodic limb movement disorder
  - Circadian Sleep Phase Disorders
  - Parasomnias
- Medical and Mental Health
- Situational factors:
  - Stress
  - Jet lag
  - Shift work
- Acute medication effects:
  - Alcohol
  - Amphetamines
  - Caffeine
  - Antidepressants
  - Steroids
  - Levadopa
  - Nicotine
  - Calcium Channel blockers
  - Beta agonists and antagonists
- Withdrawal effects:
  - Benzodiazepines
  - Barbiturates
  - Alcohol

Inadequate Sleep Hygiene

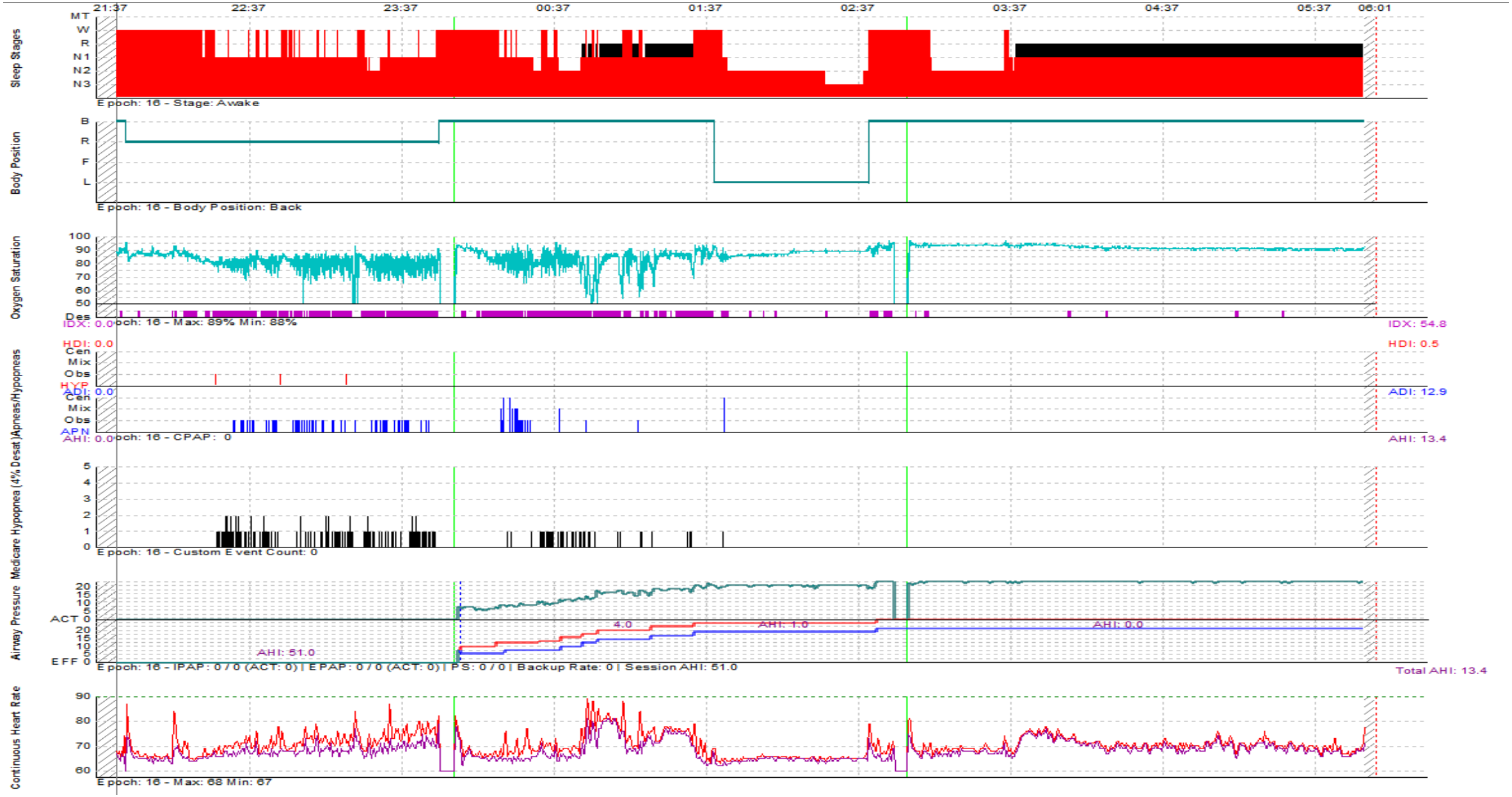
- Variable sleep schedule
- Daytime napping*
- Bed used for other activities
- Poor sleep environment
- Use of sleep-disruptive products
  - Caffeine, tobacco, alcohol
  - Electronic devices

Dysregulation of Sleep Homeostasis

More Time awake = easier to sleep

- Compensations for prior sleep loss:
  - Napping
  - Sleeping in
  - Going to bed earlier
- Unintended effect of decreasing the amount of time spent awake
- Perpetuates insomnia

Insomnia or Survival?



Effectiveness of Sleep Hygiene?

- **Rationale:**
  - Chronic insomnia sufferers often overcompensate for lost sleep by engaging in behaviors that over time sabotage their sleep habits;
- **Mode of action:**
  - Bring awareness about habits that contribute to chronic insomnia;
  - Empower person to engage in activities that are healthy and sleep promoting;
- **Effectiveness:**
  - No evidence that effective stand-alone therapy for chronic insomnia, but effective with combined with stimulus control and sleep restriction therapy.

Insomnia Summary

- Behavioral interventions are most effective
- Acute insomnia often resolves when primary reason is resolved
- Chronic Insomnia can be
  - Lifelong
  - Formed by habit
  - Due to other medical or behavioral factors
  - Worsened by other sleep disorders

- Refer if:
  - Acute Insomnia persists for unclear reasons
  - Over the counter medications to help with sleep are being used nightly
  - Medications being used for insomnia are not effective
  - Concern about underlying reason
    - OSA
    - Hypoxemia
    - RLS
    - PLMD
    - Seizures

Common Sleep Problems in Developmentally Delayed Individuals

- Insomnia
- **Obstructive Sleep Apnea**
- Circadian Rhythm Disorders
- Hypersomnia
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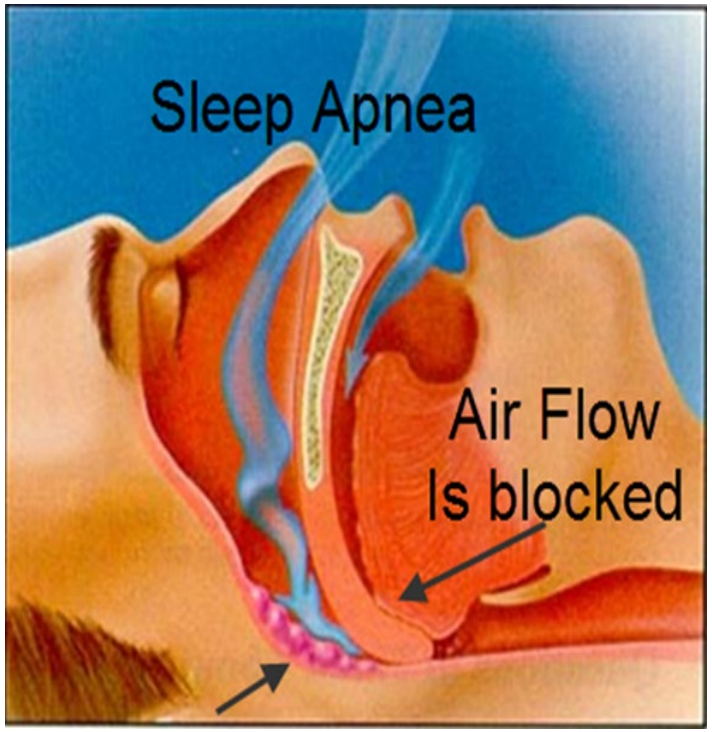
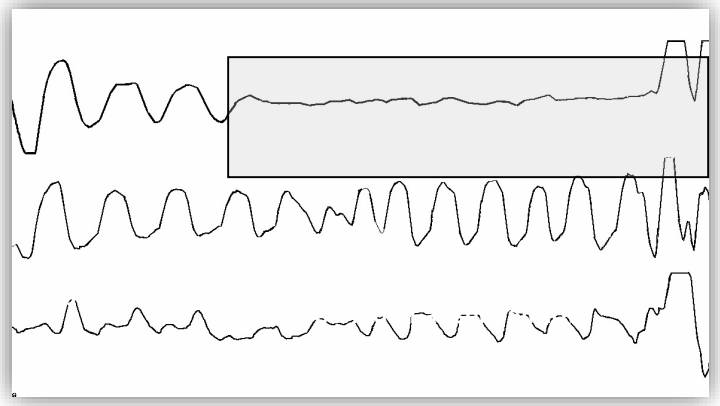
- Sleep Related Movement Disorders

Obstructive Sleep Apnea

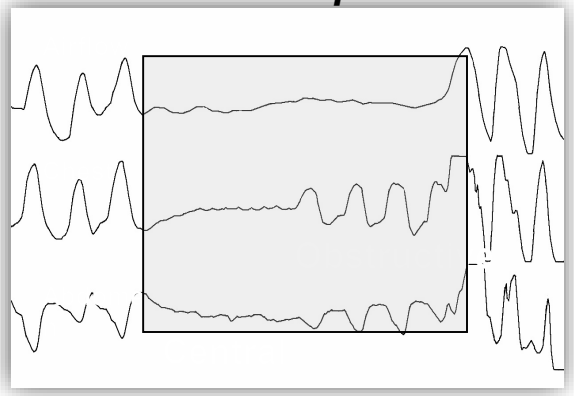
- Repeated pauses in breathing interrupting sleep
  - At least 10 second duration
  - Oxygen desaturation
  - Brain interruption
- Associated with many medical and behavioral problems
- Risk Factors:
  - Body Habitus
  - Facial Features
  - Muscle Tone



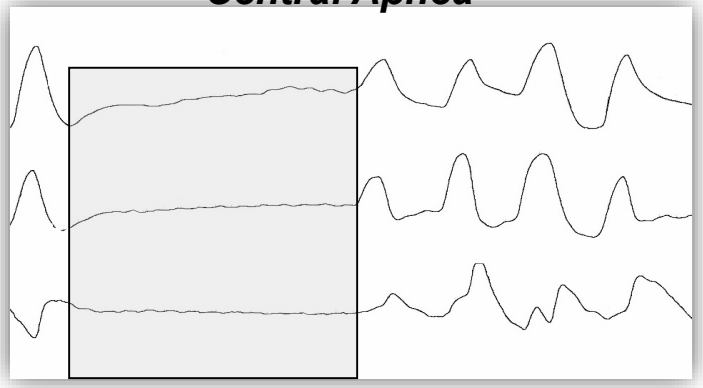
Obstructive Apnea



Mixed Apnea



Central Apnea

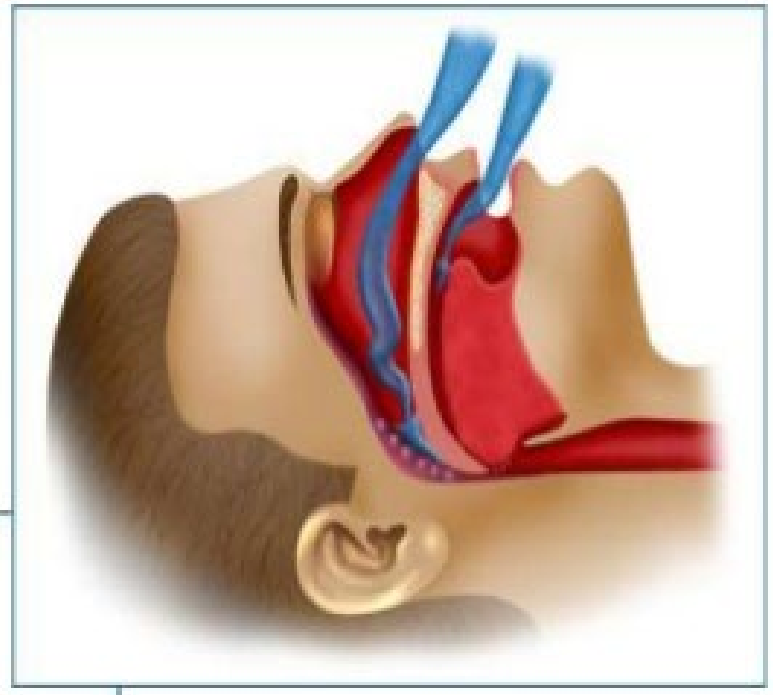


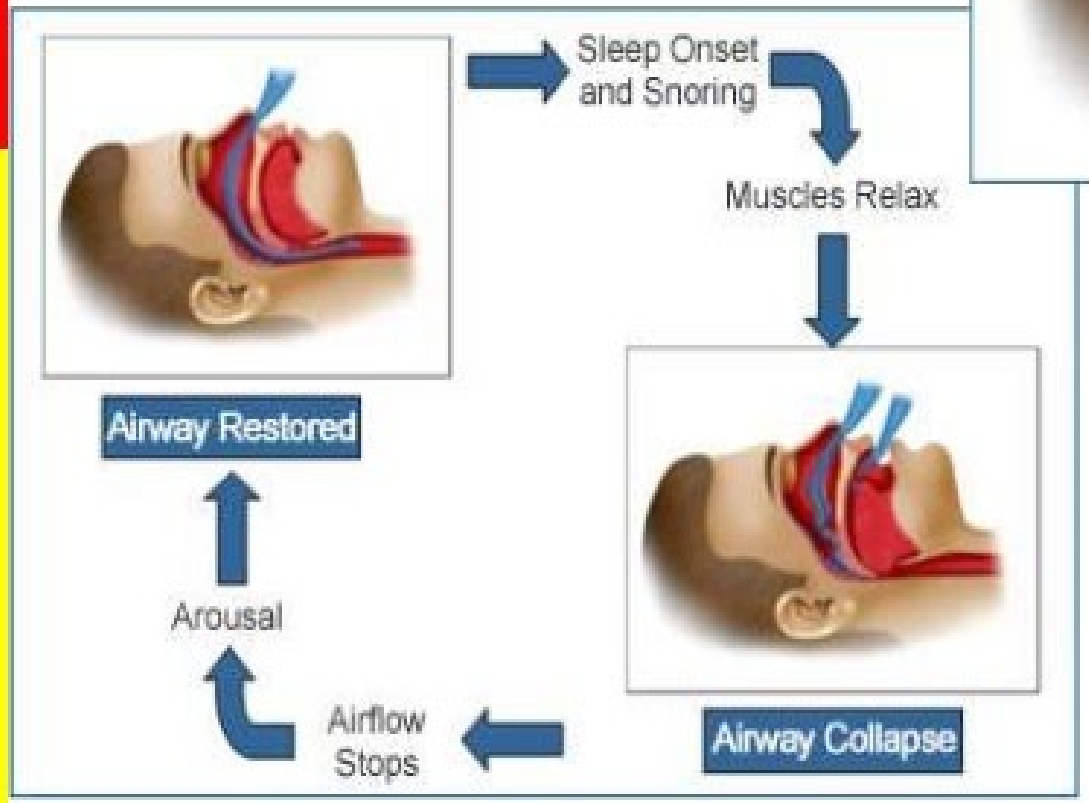
We classify sleep apnea in a PSG based upon INSPIRATORY effort during absent airflow

Central Sleep Apnea

- A lack of effort to breathe
- Dysregulation due to:
  - Brain Lesion
    - Stroke, anatomical, vascular, tumor
  - Genetic
    - Odine's Curse ("forget" to breathe)
  - Medication
    - Narcotics block Mu receptor that regulates pain and breathing
  - Poor Cardiac Function
    - Congestive Heart Failure, Atrial Fibrillation
    - Signal to brain is "old news"

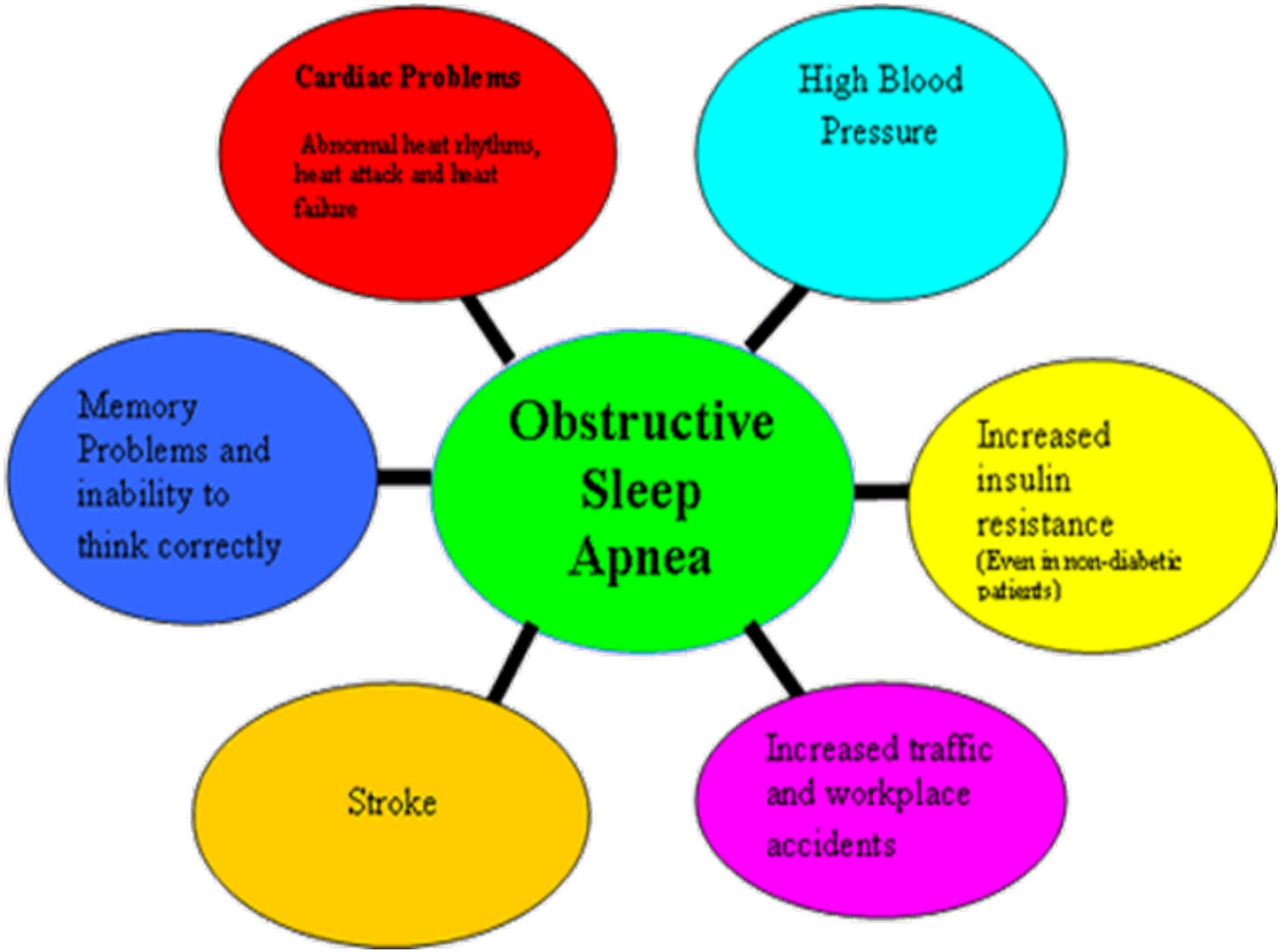
Obstructive Sleep Apnea





Symptoms:

- ✓ Snoring
- ✓ Pauses in breathing during sleep
- ✓ Waking up gasping for air
- ✓ Excessive sweating during sleep
- ✓ Restless sleep
- ✓ Frequent nocturnal awakenings
- ✓ Nocturia
- ✓ Morning headache
- ✓ Excessive daytime sleepiness


Cardiac Problems
Abnormal heart rhythms, heart attack and heart failure
High Blood Pressure
Memory Problems and inability to think correctly
Obstructive Sleep Apnea
Increased insulin resistance
(Even in non-diabetic patients)
Stroke
Increased traffic and workplace accidents

Signs/Symptoms May Vary With Age

- **Children**
  - Pauses in breathing
  - Secondary enuresis
  - Hyperactivity
  - Morning headache
- **Middle Age**
  - Pauses in breathing
  - Snoring
  - Excessive daytime sleepiness
  - BMI > 35, Neck > 16/17
- **Older > 60 years**
  - Not feeling well rested
  - Nocturia ≥ 3

Physical Findings on Exam Which May Predispose to OSA

BMI > 35

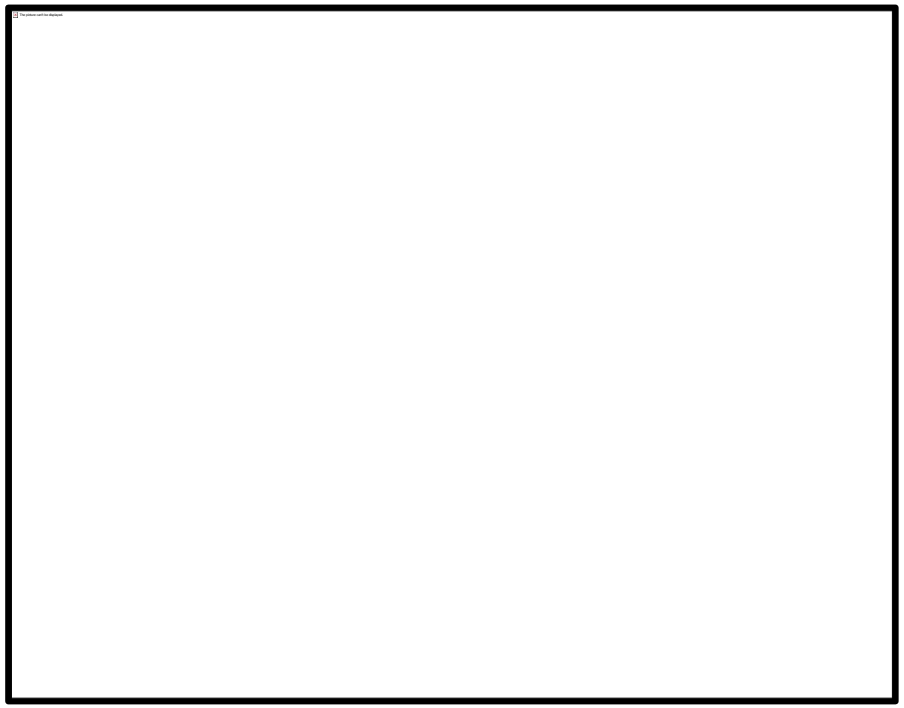
Neck Circumference

- > 16 in women
- > 17 in men

Physical Findings on Exam Which May Predispose to OSA

Crowded Oropharynx

- Large uvula
- Large Tongue
- Tonsil hypertrophy
- Small Airway
- High arched narrow palate
- Low laying palate

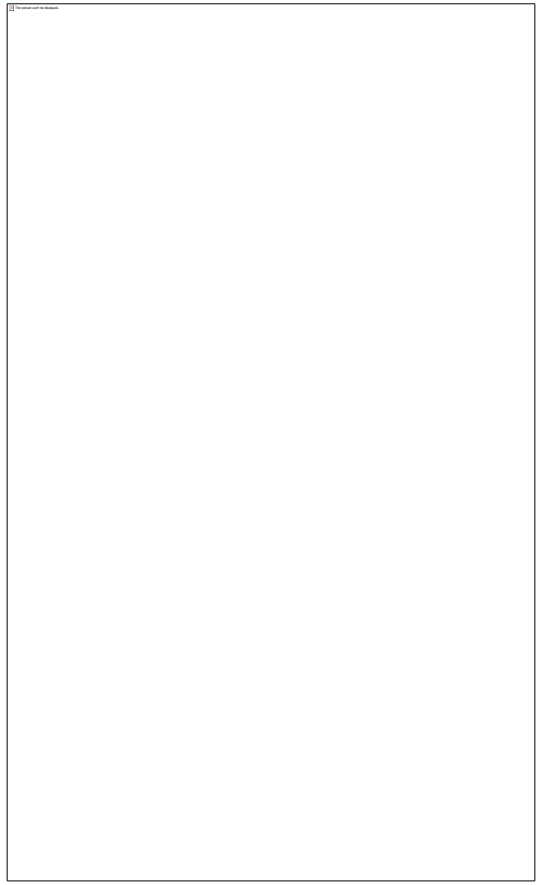


http://yoursmileyourstyle.com/files/2014/05/What-your-dentist-looks-for-in-diagnosing-sleep-apnea.jpg

Physical Findings on Exam Which May Predispose to OSA

Physical Findings on Exam Which May Predispose to OSA

- Chronic nasal congestion
- Nasal speech
- Obligate mouth breather
  - adenoidal hypertrophy
- Mandibular retrognathia
- Midface Hypoplasia
- Floppy Eye Syndrome
  - AKA Ectropion
  - 38/45 patients (85%) had OSA
  - 65% had severe OSA



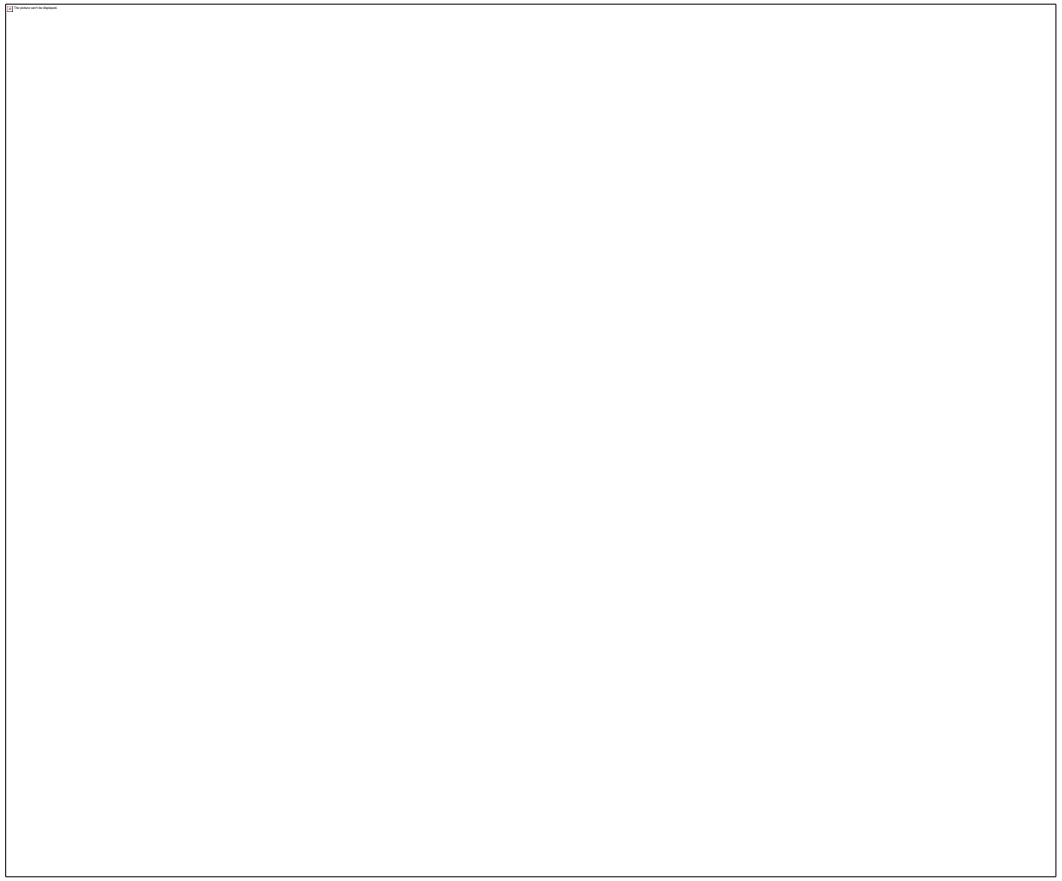
http://www.imo.es/wp-content/uploads/2011/02/ectropion-antes.jpg

Screening Tools for Obstructive Sleep Apnea (OSA) in Adults with NDD/ID

GASP Screen for OSA

- During the night do you?
  - **G** gasp or choke?
  - **A** stop breathing?
  - **S** snore loudly
  - **P** perspire (sweat);
- Do you have trouble sleeping?
- Is your sleep refreshing?
- Are you sleepy in the day?
- Take naps?

Stop-Bang Questionnaire



Treatment for OSA

CPAP (Continuous Positive Airway Pressure) Therapy

This most common treatment is now available in smaller sizes that are gender specific, noiseless, and more comfortable.

Dental Devices

Small and easy to wear, dental devices are an excellent treatment for mild to moderate sleep apnea.

Psychiatric

Behavioral therapies are often helpful in desensitizing treatment options, improving overall sleep hygiene, and alleviating underlying causes of anxiety and depression.

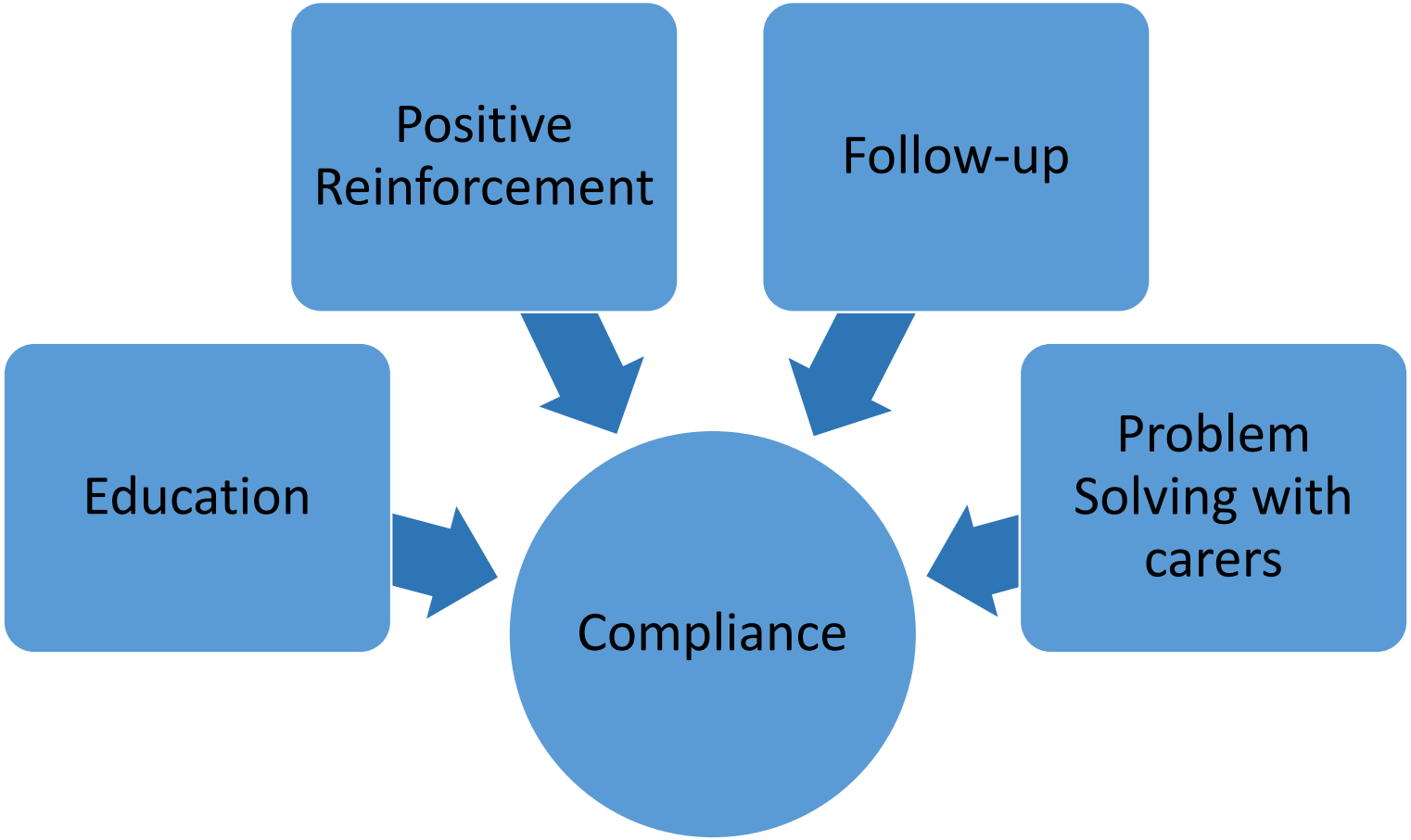
Weight Loss

A loss of 10% of body weight may be an effective treatment for some sleep apnea cases.

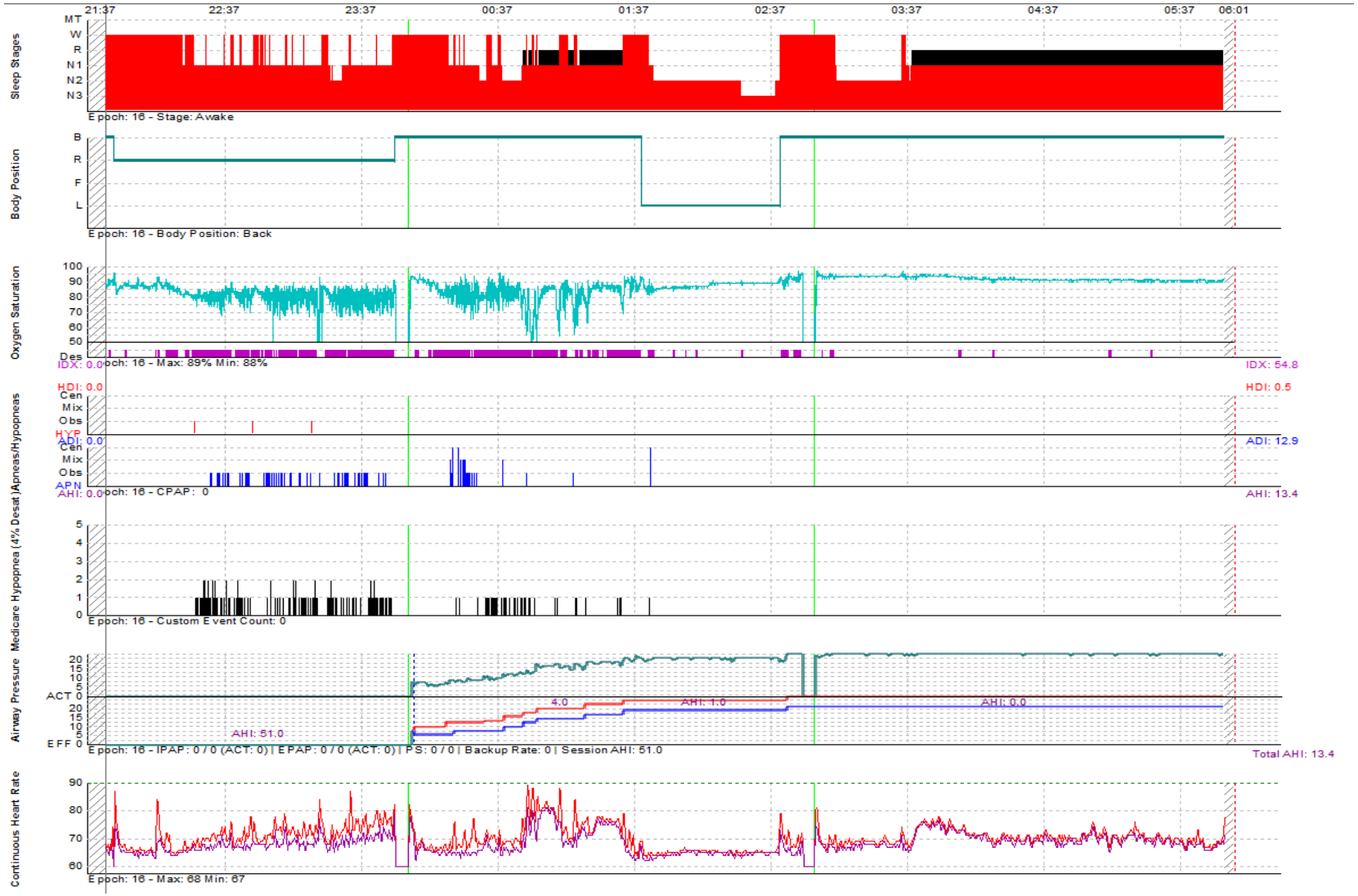
Surgical

New treatments require less recovery time, and some can be performed in an outpatient setting.

Factors that Improve PAP Compliance



Before and After PAP



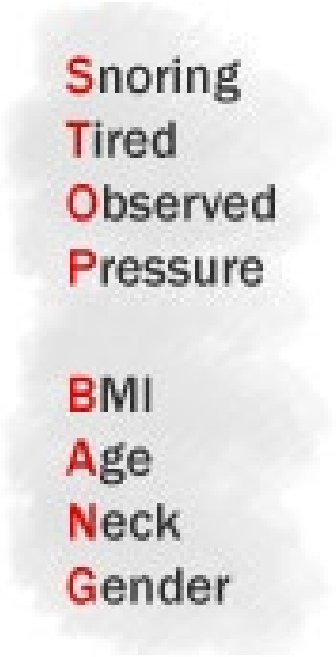
OSA Summary

Most Common Symptoms:

- Snoring
- Pauses in Breathing
- Excessive Daytime Sleepiness

Treat to Reduce Morbidities:

- Cardiovascular
- Neurological
- Behavioral



Common Sleep Problems in Developmentally Delayed Individuals

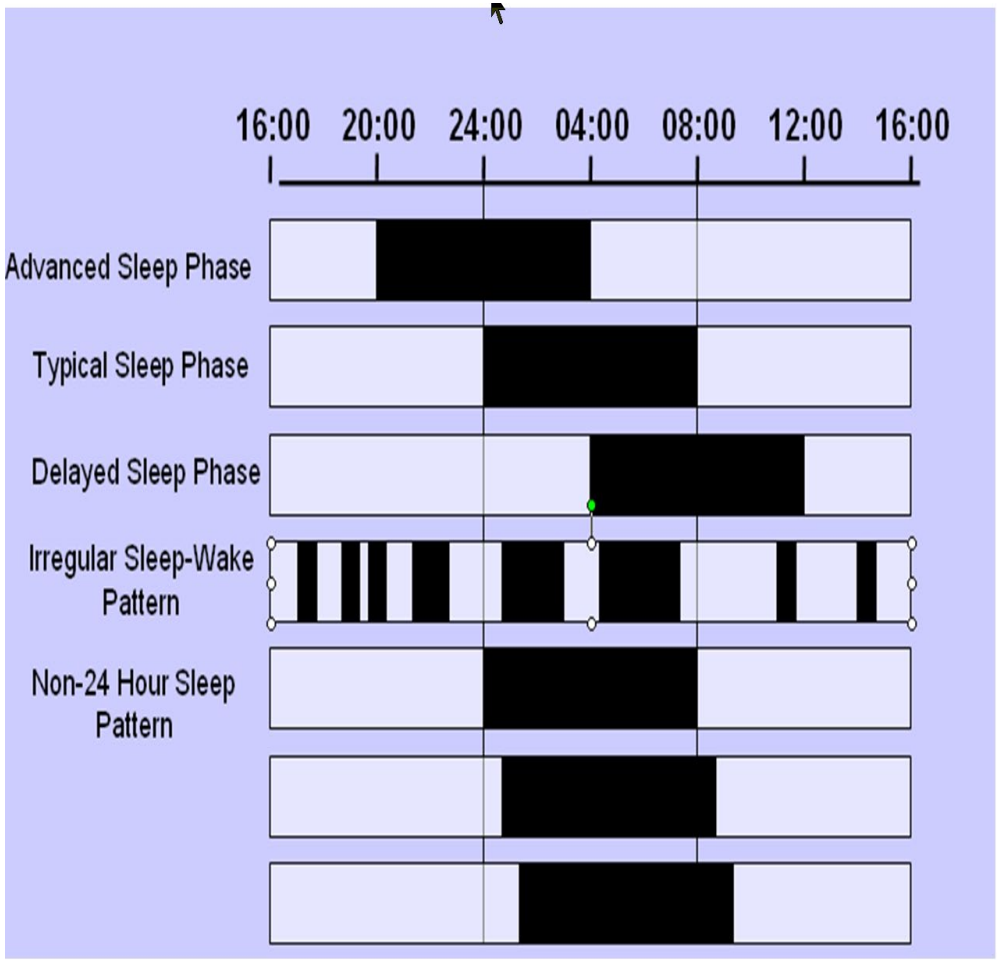
- Insomnia
- Obstructive Sleep Apnea
- **Circadian Rhythm Disorders**
- Hypersomnia
- Parasomnias
- Sleep Related Movement Disorders

Screening for Circadian Rhythm Disorders

- What time do you naturally prefer to go to bed/get up?
- Is it easier for you to go to bed later and get up later?
- If you could sleep when you prefer would you have trouble sleeping?
- Have you always kept these hours? Since childhood?
- Is there anyone in your family who prefers to go to bed really late or get up really early?
- Does you bedtime move around the clock in a regular fashion?

Adults with NDD Prone to Circadian Sleep/Wake Rhythm Disorders

- Misalignment of internal sleep/wake rhythm and the desired (or required) time for sleep
- Desire for sleep and wakefulness at inappropriate times
- Risk Factors
  - Intrinsic brain abnormalities
  - Blindness
  - Genetic predisposition



What is the Hype about Chronotype?

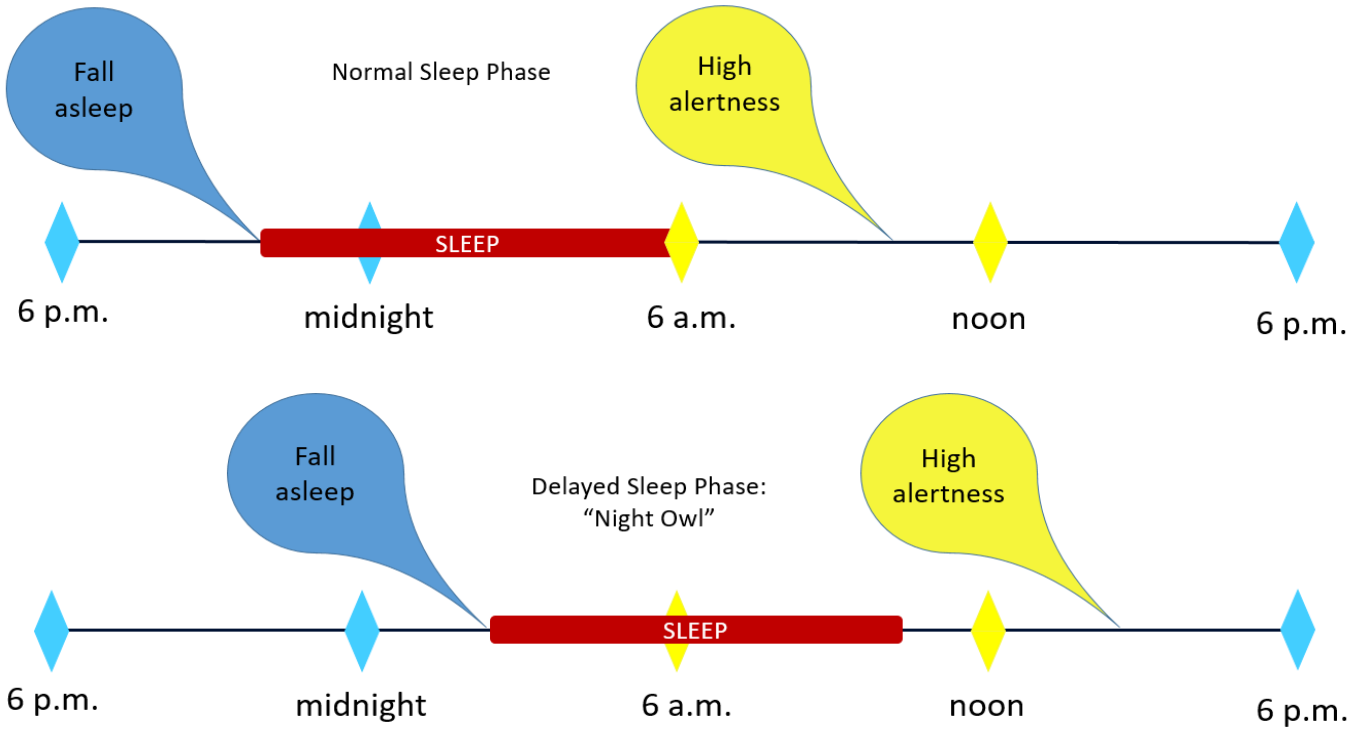
Chronotype= inter-individual differences in the phenotypic expression of behavioral outputs regulated by the circadian system

ARE YOU A LARK or an OWL?	MORNING LARK	NIGHT OWL
At Your Best	Late morning	Late afternoon, evening
Alarm Clock	Not necessary	Several and spread out
Morning Disposition	Mary Sunshine	Scrooge
Late-night Disposition	Party Pooper	Party Animal
Favorite Time To Exercise	Dawn	Dusk
Breakfast	Loves to lounge over breakfast	Skip it or dash out of the house with an apple
Travel	Prone to jet lag especially traveling west	Adapts better to jet lag better traveling west
Age	Many people over 60	Teens and young adults
Sleep Quotient	Sleep soundly	Sleep-deprived

Delayed Sleep Phase Syndrome

- May look like sleep onset insomnia
- Inability to arise in the morning
- Normal sleep if initiated at a delayed bedtime
- Bedtimes & wake times are later on vacations
  - e.g., 4 a.m. – 12 p.m. sleep period
- Peak onset in adolescence
- Differentials include:
  - Sleep-onset insomnia
  - Bipolar disorder
  - Inadequate sleep hygiene

Delayed Sleep Wake Phase

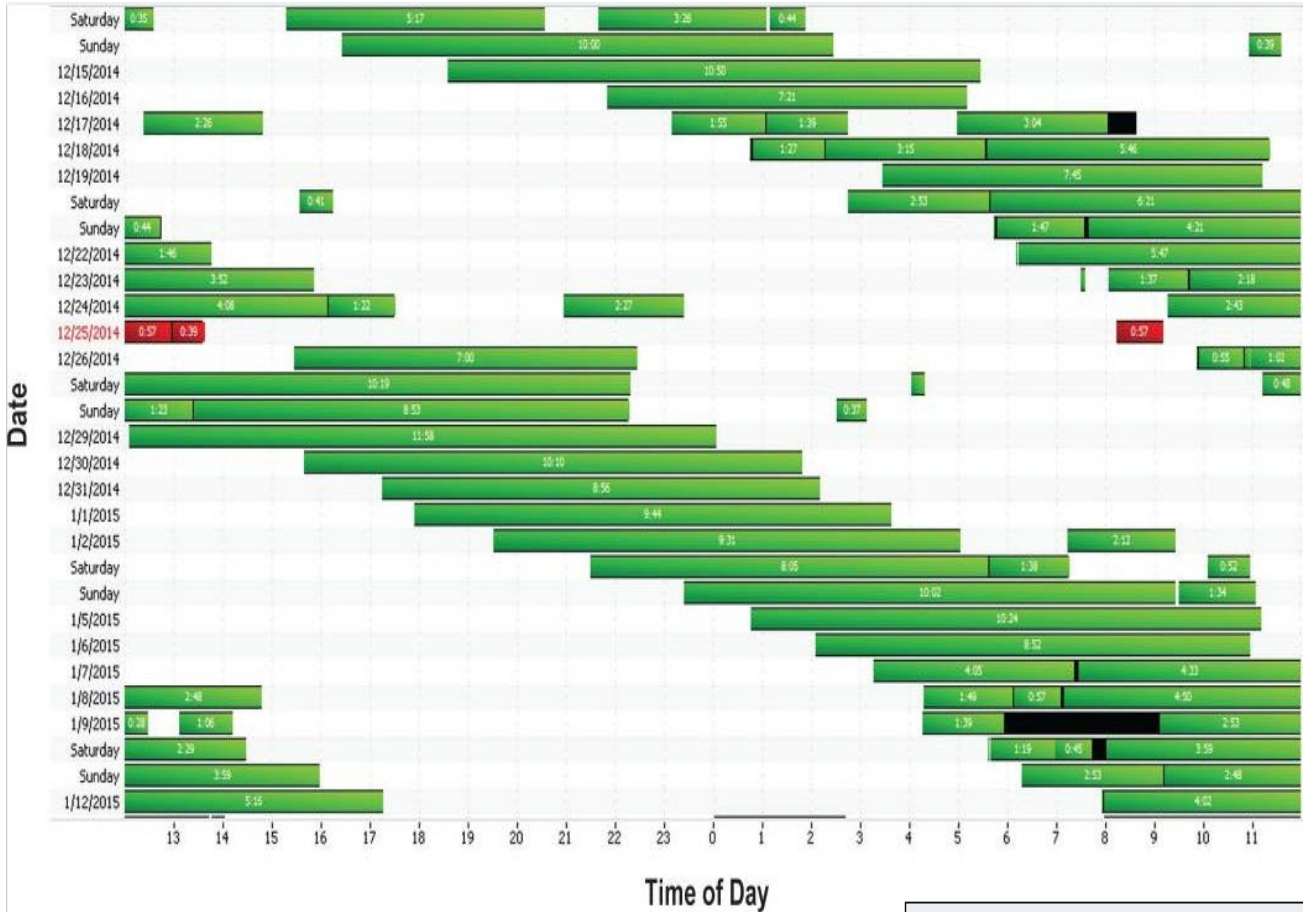


Irregular Sleep/Wake Disorder

- Patients can complain of insomnia and/or excessive daytime sleepiness (EDS);
  - Diagnosis based on sleep logs and/or actigraphy recorded for 1-2 weeks
  - Shows ≥3 distinct sleep episodes within 24-hour sleep period
  - Total sleep times across 24-hours are normal for age

Non-24 h Running Sleep-Wake Circadian Rhythm Disorder

- More common in blind individuals
- Progressive delay of sleep period by 1 hour per day with relatively stable sleep duration = non-24 h



Case:

During Summer Break, a high-school student preferred to sleep from 2am-10 am every day and felt he slept better than when he is in school. The night before his first day back to school, he tried to go to bed at 10pm but his mind was racing and he could not fall asleep until 2:30 am. He then had to wake up for school at 6:30 am.

What is his primary sleep issue?

A) Initial Insomnia

B) Anxiety about returning to school

C) Circadian Sleep phase delay

D) Poor sleep hygiene

E) Bipolar Disorder

Common Sleep Problems in Developmentally Delayed Individuals

- Insomnia
- Obstructive Sleep Apnea
- Circadian Rhythm Disorders
- **Hypersomnia**
- Parasomnias
- Sleep Related Movement Disorders

Hypersomnia

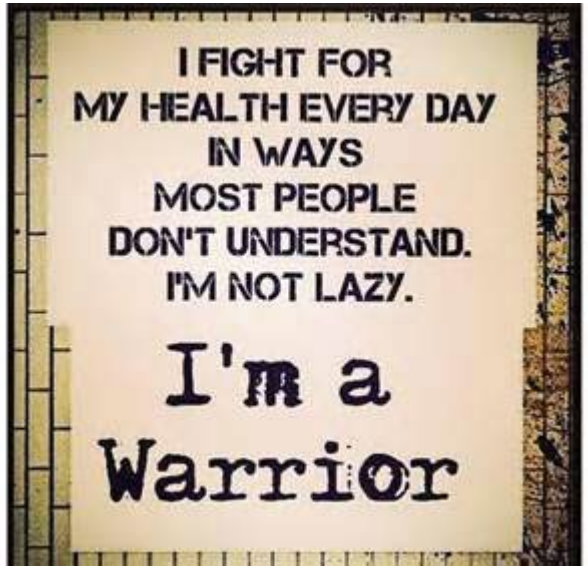
- Too Much Sleep
  - Excessive duration of sleep
  - Excessive depth of sleep
  - Excessive frequency of sleep episodes
- Risk Factors
  - Intrinsic
  - Genetic
  - Medication

Likely Hypersomnia Disorders in NDD/ID

- Hypersomnia due to a medical disorder
  - Parkinson's disease
  - Post traumatic
  - Genetic disorders
    - Prader Willi
    - Myotonic dystrophy
    - Moebius syndrome
    - Fragile X syndrome
  - Brain tumors
  - CNS infections/lesions
  - Endocrine disorders
    - Hypothyroidism
  - Metabolic encephalopathy
  - Residual sleepiness in those with adequately treated OSA

Secondary Hypersomnia

- Hypersomnia due to a medication
  - Sedating medication
  - Substance abuse
  - Stimulant withdrawal
- Hypersomnia associated with a psychiatric disorder
  - Mood disorder
  - Somatoform disorders
  - Schizoaffective disorder
  - Adjustment disorder
  - Personality disorders
- Insufficient sleep syndrome
  - Common in teens



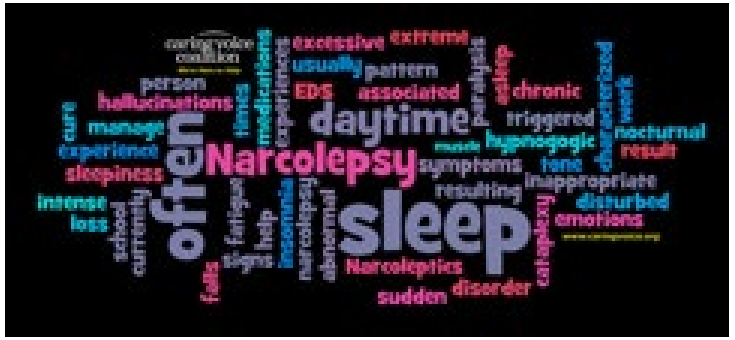
Hypersomnia Disorders

- Idiopathic hypersomnia
- Klein-Levin Syndrome
  - Hypersomnia
    - 2-5 week duration
    - Recurrent at least < every 18 months
  - At least one during episode:
    - Cognitive dysfunction
    - Anorexia or hyperphagia
    - Disinhibition
    - Altered perception

Hypersomnia Disorders

- Narcolepsy
  - Due to loss of orexin secreting neurons
  - Genetic predisposition
  - Autoimmune component
- Symptoms:
  - Sleep attacks
  - Sleep Onset latency of < 8 minutes
  - Sleep Onset REM period
  - Sleep Onset hallucinations
  - Sleep/wake instability
    - Too sleepy in the day
    - Hard to sleep soundly during the night

- Narcolepsy Type I
  - Cataplexy
    - Sudden loss of muscle tone
    - Precipitated by strong emotions
    - Retain Consciousness
- Narcolepsy Type II
  - No cataplexy



Hypersomnia Summary

- A known factor in many neurodevelopmental syndromes due to :
  - Intrinsic factors
  - Medical morbidities
  - Medications
  - Other sleep disorders
- Refer if:
  - Concern for underlying cause
    - OSA
    - Seizures
    - Overmedicated

Alertness Management Strategies

Increase exposure to bright light during the morning

- 20-30 minute intervals if possible
- 10,000 lux or natural light outside
  - Improves daytime function
  - Alertness
  - Mood

Wear a sleep mask during daytime sleep

Wear sunglasses if bright outside shortly before sleep time

- increase sleep consolidation
- over-ride circadian light signal for wakefulness

Common Sleep Problems in Developmentally Delayed Individuals

- Obstructive Sleep Apnea
- Circadian Rhythm Disorders
- Insomnia
- Hypersomnia
- **Parasomnias**
- Sleep Related Movement Disorders

Parasomnias

- Unwanted nocturnal behaviors
  - Simple or Complex
  - Routine behaviors
  - Inappropriate behaviors
- Consciously unaware
- Familial Pattern
  - Neither parent affected
    - 22% of children sleepwalk
  - One parent affected
    - 45%
  - Both parents affected
    - 60%
- Predisposing, priming and precipitating factors involved

NREM Parasomnias

- Often in the first third of the night
- More Common in children
  - Typically from NREM 3 sleep
- Increased with:
  - Sleep deprivation
  - Sickness
  - Stress
  - Side effects to medications

- Sleep walking
  - *Somnambulism*
  - Sleep Related eating disorders
- Sleep talking
  - *Somniloquy*
- Groaning during Sleep
  - *Catathrenia*
- Bedwetting
  - *Enuresis*

Parasomnias During NREM Sleep

- Night Terrors
  - Episodes of abrupt terror
  - Intense fear
  - Autonomic arousal
  - Inconsolable
  - Eyes open
  - Brief to 30+ minutes

- Confusional Arousals
  - Mental confusion or confused behavior
  - Absence of terror or ambulation

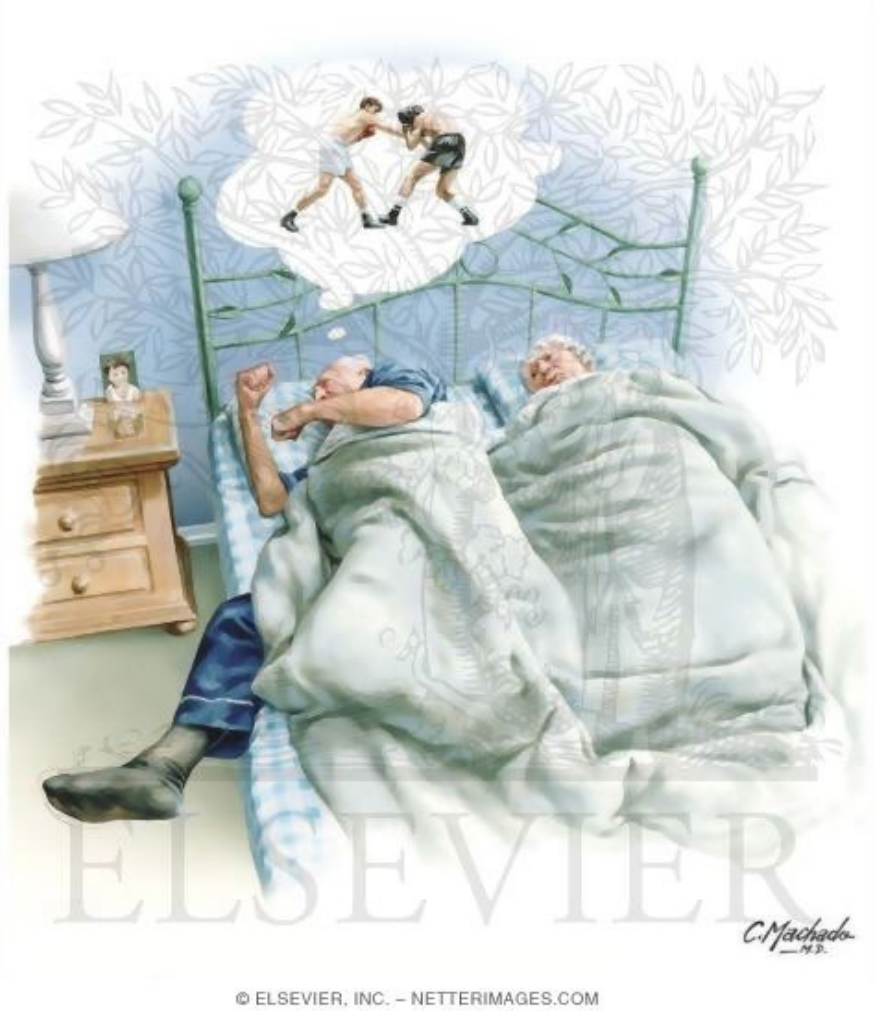
- Shorter duration if person is left alone/decrease stimulation

Parasomnias During REM Sleep

- Nightmares
- Sleep Paralysis
  - Awake but unable to move
- Sleep related hallucinations
  - Hypnogogic-When falling asleep
  - Hypnopompic-When waking up

Parasomnias During REM Sleep

- REM Behavioral Disorder
  - Dream enactment
  - Usually Brief
  - Recall intact upon awaking
  - Themes of being pursued/fear
  - Associated with neurodegenerative diseases
    - Predate onset of Alpha- synucleinopathies by years
      - Parkinson's Disease
      - Multiple systems atrophy
      - Dementia with Lewy Bodies
    - Lesions affecting brain stem
      - Multiple Sclerosis
      - Narcolepsy
      - Stroke
    - Medications
      - Antidepressants



Night Terrors-Occur in N3 sleep	Nightmares-Occur in REM sleep
Eyes open	Eyes closed
First half of the night	Second half of the night
Can be associated with temporal lobe epilepsy	Muscles are paralyzed- can wake from fright and still have sleep paralysis
Hard to wake during episode, no recall	Wakes easily and can usually recall

Case:

The mother of a young child with Autism and a seizure disorder are worried about changes in his sleep since he started going to daycare. She reports events where he wakes up calling out in the night. When one of his parents goes to the child's bed, their son is staring, wide-eyed, sitting up and screaming in fear. They try to reassure him while he continues to scream and moan for a while until collapsing onto the bed asleep again. He seems like himself the next morning and usually does not recall the events.

He has been crying every morning when dropped off and several kids in his class have been sick recently. A likely explanation for this child's behavior is:

A) Frontal lobe seizures

B) Growing Pains

C) Narcolepsy

D) Night Terror

E) Nightmare

Nightmare Re-imaging Therapy

- Set aside time next day to think through your nightmare and discuss it with someone;
- Identify worse moment in your nightmare:
  - Where are you? What are you aware of? What is happening?
- What emotions are you feeling at that worst moment?
  - Identify your emotions and what you feel in your body either during the nightmare or after waking up;
- What would you prefer to feel in that moment?
- How would the story need to be changed for you to feel that way.

Parasomnia Summary:

- Parasomnias can be caused by:
  - Sleep deprivation
  - Sickness
  - Stress
  - Side effects to medications
  - Sleep disorders

- Refer if:
  - Occur nightly
  - Causing safety concerns
  - Persist over long periods

- Often transient or improved with increased sleep or removal of offending agent

Common Sleep Problems in Developmentally Delayed Individuals

- Obstructive Sleep Apnea
- Circadian Rhythm Disorders
- Insomnia
- Hypersomnia
- Parasomnias
- **Sleep Related Movement Disorders**

Sleep Related Movement Disorders

- Restless Leg Syndrome

U- Urge to move limbs

R- Rest makes it worse

G- Getting up/moving helps

E- Evening or night

S- Symptoms not due to other cause

Sleep Related Movement Disorders

- Restless leg syndrome
  - Bothersome while awake
  - Associated with iron deficiency
    - Ferritin < 50
  - Familial
  - Overlap with Periodic Limb Movements Disorder
    - 80% of those with RLS have PLMD
- Periodic Limb Movement Disorder
  - During Sleep
  - Movements interrupt/worsen sleep
  - Overlap with RLS
    - 20% of those with PLMD have RLS
- Restless sleep Disorder is new diagnosis in childhood
  - Shares risk factors and treatment with RLS/PLMD

Non-pharmacologic Treatment for RLS, PLMD and Restless Sleep Disorder

- Remove or reduce contributing factors
  - Caffeine
  - Low activity
  - SSRI and SNRI Antidepressants*
    - Take in a.m. rather than p.m.
    - Change to bupropion
- Eat iron rich foods (lean meats, dark leafy greens)
- Start oral iron therapy if ferritin < 75 or iron saturation < 45%
- Exercise during the day
- Weighted blankets?

Sleep Related Movement Disorders

- Sleep Related Rhythmic Movement Disorder
  - Repetitive, stereotyped and rhythmic motor behaviors
    - Body rocking
    - Head banging
    - Leg banging
  - Occurs when drowsy or asleep
  - Usually benign
  - Education and reassurance is primary treatment

- A “problem” when:
  - Interferes with sleep
  - Daytime impairment
  - Risk of Self Injury

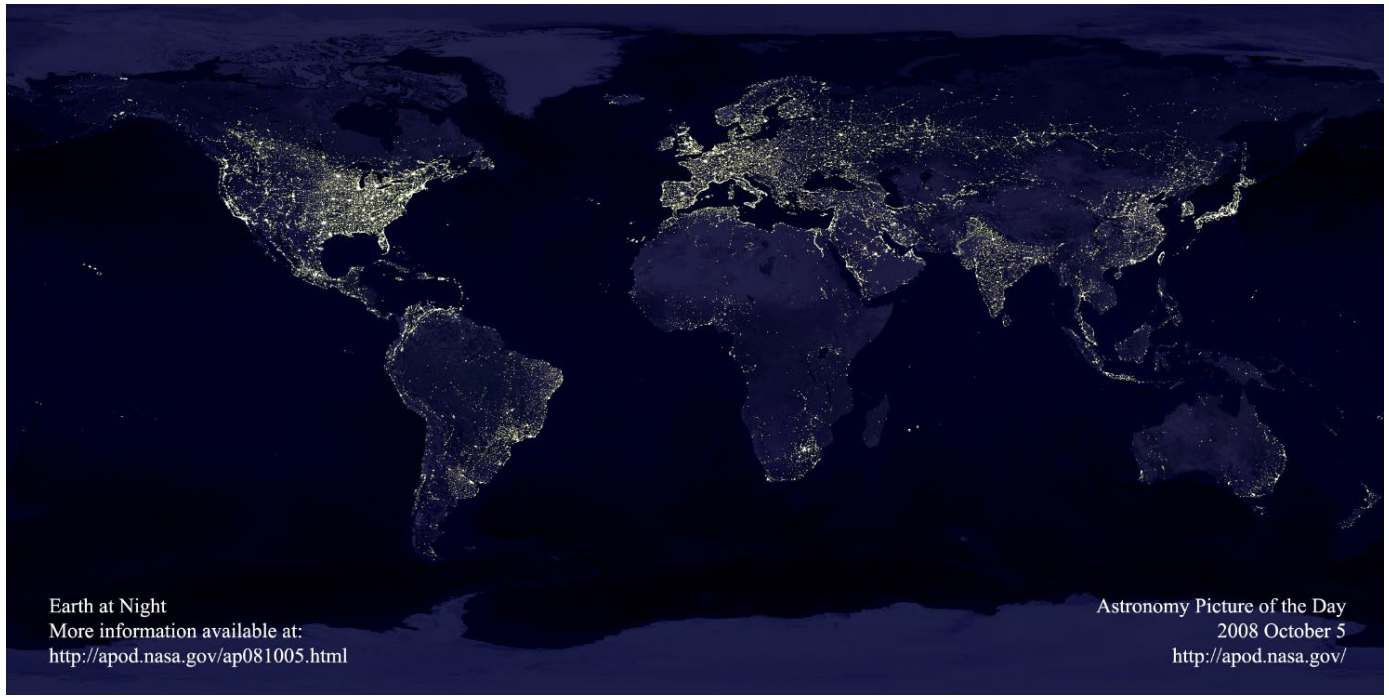
Sleep Related Movement Disorder Summary

- RLS can mimic insomnia
  - Check ferritin level is > 50
- Periodic Limb Movements may not be a disorder:
  - if not interrupting sleep
  - not causing daytime dysfunction
- Rhythmic Movements can be a coping tool
- Dream enactment may be a harbinger of a neurodegenerative illness

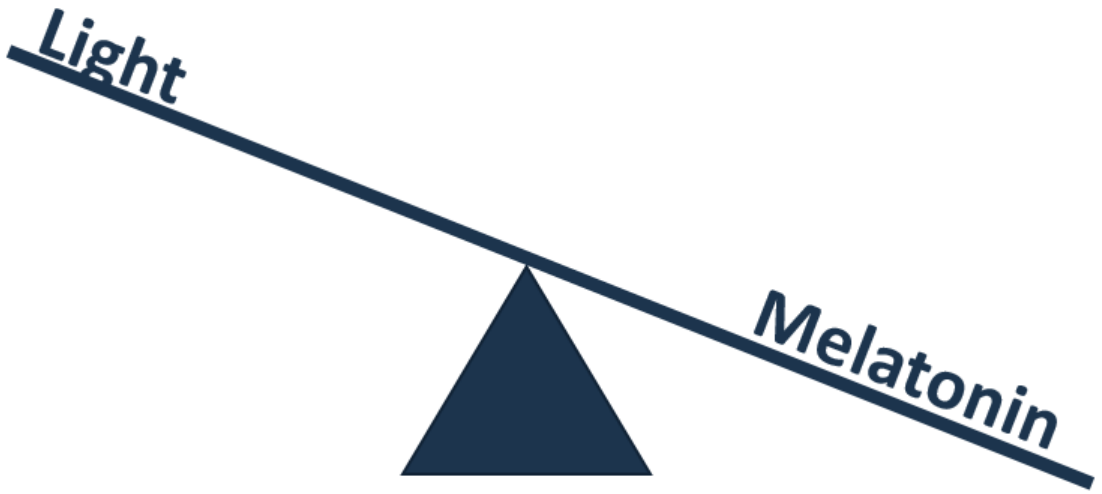
- Refer if:
  - Daytime functional impairment
  - Safety concerns

Improving Sleep in People with NDD/ID

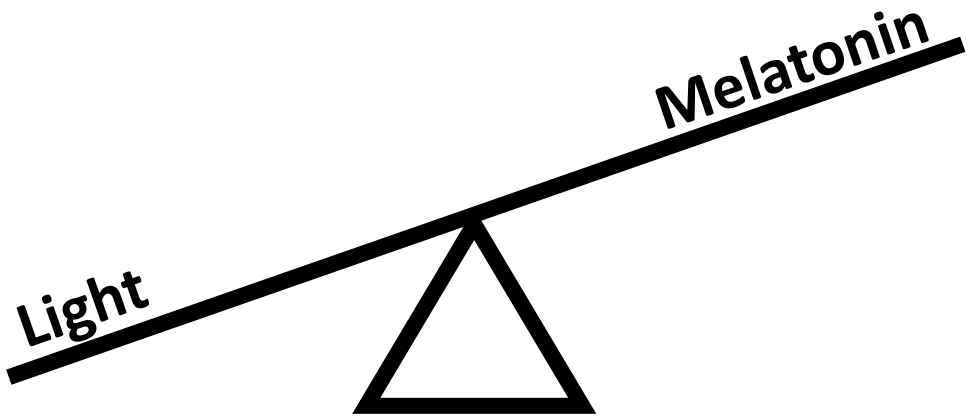
- Biological interventions
  - Treat underlying contributors
  - Pharmacological and alternative treatments
- Social-behavioral interventions
  - Sleep Hygiene
  - Exercise-related
- Educational and behavioral interventions well accepted and favorably received


Earth at Night
More information available at:
http://apod.nasa.gov/ap081005.html
Astronomy Picture of the Day
2008 October 5
http://apod.nasa.gov/

See the Light
About Avoiding Light Before Sleep



Turn Off Electronics at Least 30 Minutes Before Going To Bed

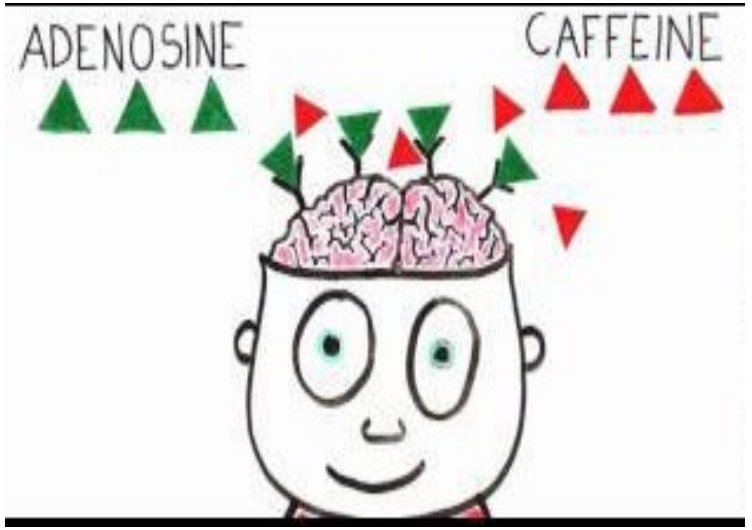


Cool Down For Better Sleep

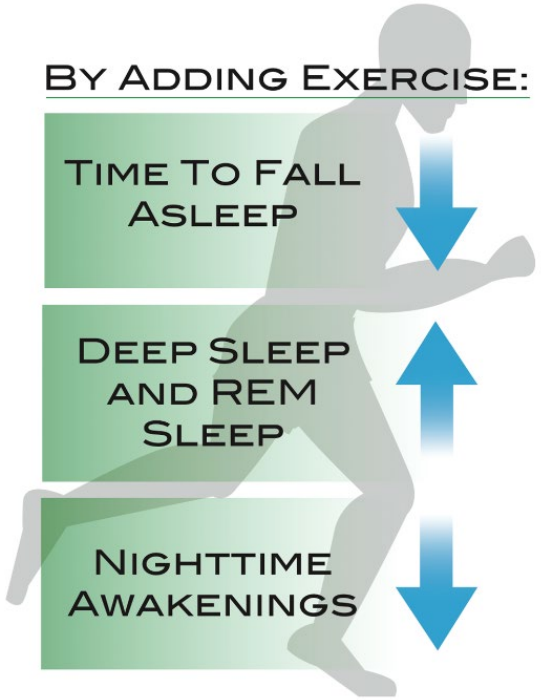
- Environmental temperature:
  - A cooler environment promotes sleep
  - 65-68 degrees is ideal
- Core body temperature:
  - Easiest to fall asleep as our core body temperature is falling
  - Easiest to nap during the mid afternoon

Caffeine Helps With Fatigue But Interferes With Sleep

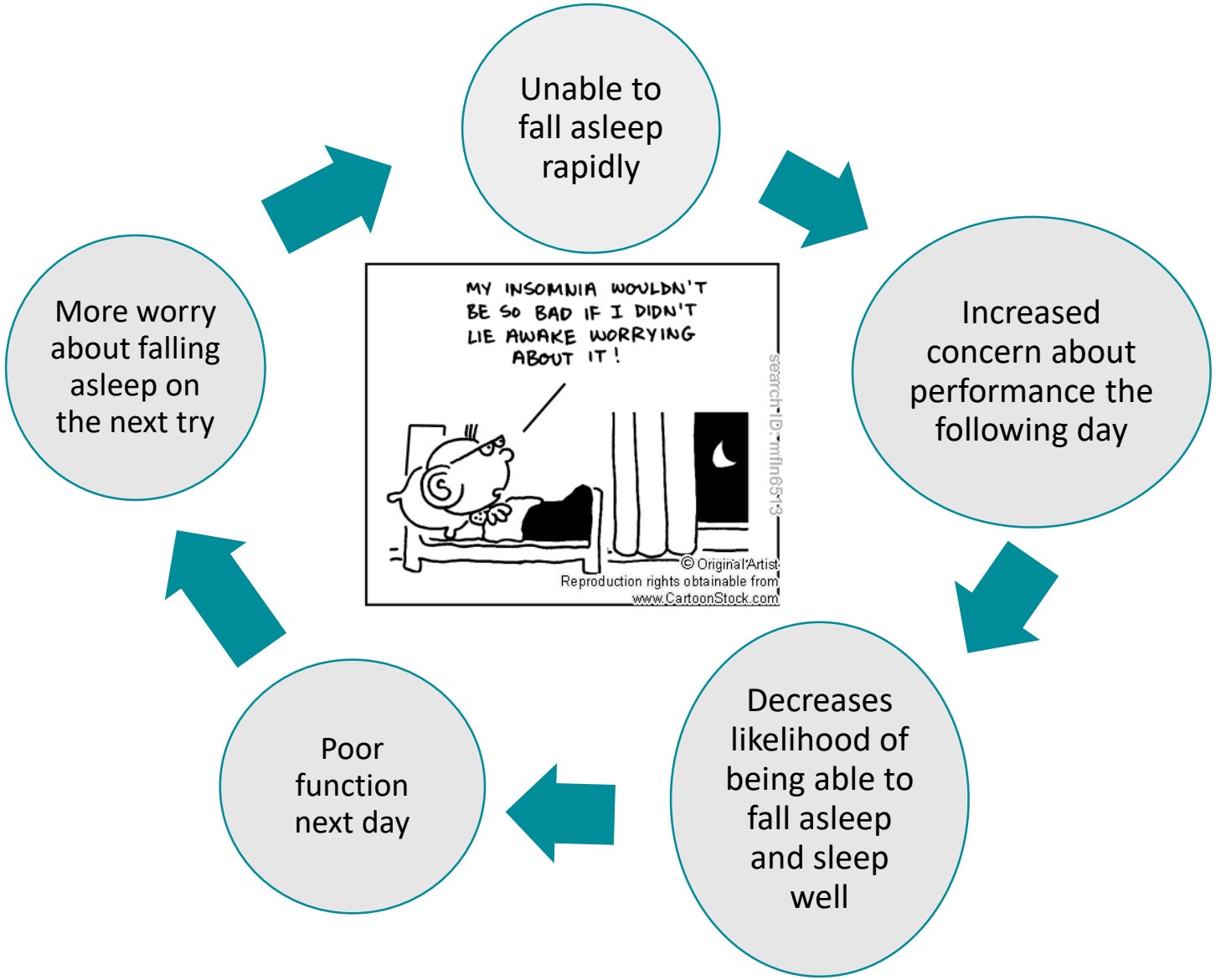
- Caffeine blocks adenosine
  - More adenosine builds up the longer you are awake
- Adenosine signals the brain about becoming sleepy
- Adenosine is washed out of the brain during sleep
- Caffeine stays in your system for 10-12 hours
  - Tricks the brain into ignoring sleepiness even when you are tired



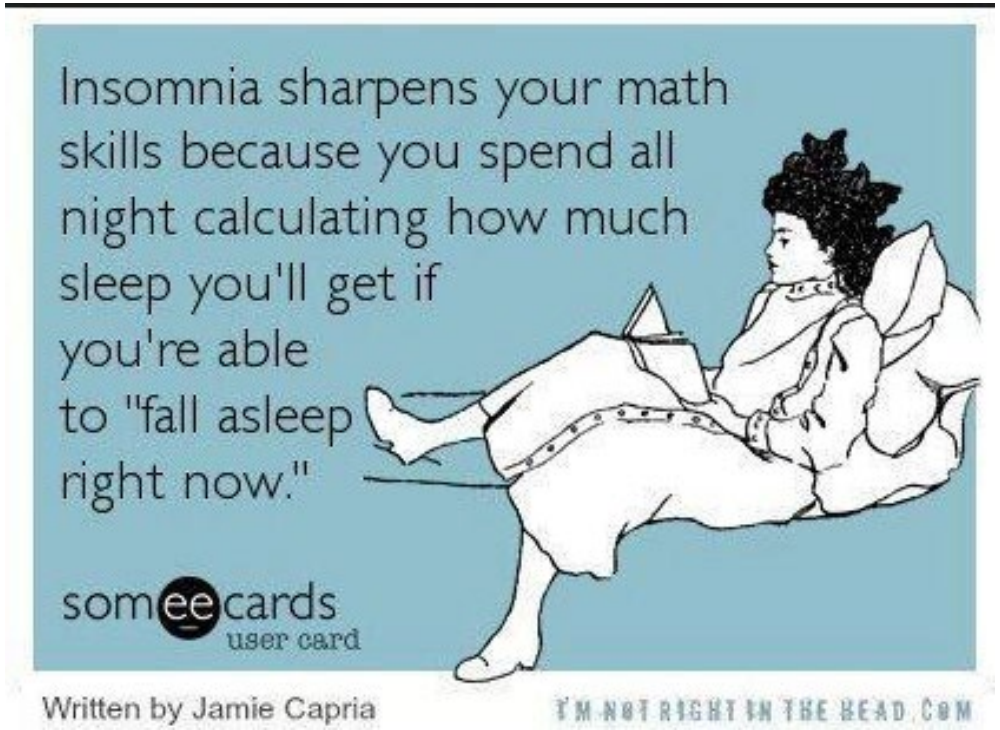
Increase Activity to Improve Sleep And Decrease Fatigue



Worrying About Sleep Makes It Harder To Sleep



Avoid Looking At The Time When Having Trouble Sleeping



Case: Mr. Willi

Mr. Prader-Willi is a 39 year old morbidly obese male who reports that he wakes every morning with a headache and feels tired during the day.

He sleeps an average of 12 hours a night.

He often wakes up hungry in the middle of the night and sneaks to the kitchen to get a snack, while other times he wakes up with crumbs in his bed though does not remember getting up to eat.

His roommate complains that he is “noisy” at night, which makes Mr. Willi feel persecuted.

Case: Mr. Willi:
Key Points

- Some developmental disorders, like Prader-Willi, have known hypersomnia
- Obesity is a risk factor for OSA
- Waking unrefreshed after sufficient sleep and taking day time naps is a major red flag for OSA
- OSA is a risk factor for parasomnias due to interruptions in sleep
- OSA contributes to problems with glucose regulation and impulse control
- Snoring may bother others more than the patient
- Obesity increases the likelihood of obesity hypoventilation
  - Morning headache due to accumulation of CO2 due to insufficient expiration/hypoventilation
  - Resolves when CO2 is “blown off” with normal respirations when awake

Case: Ms. Nellie

Mrs. Nellie is a 57 year old female with autism spectrum disorder who has always had insomnia and been a nervous person, but over the last several years has been having even more difficulty falling asleep and has been waking up in the middle of the night “in a panic”.

She sometimes wakes and can’t move her body for several minutes, which is very frightening to her. Now she fears going to sleep.

She returns for follow up after starting lorazepam 1mg at bedtime noting that she is falling asleep faster, but still wakes with anxiety.

She has been having memory problems.

She wakes to urinate at 3am and can’t return to sleep.

Sometimes rocking her body helps her go to sleep.

Case: Ms. Nellie
Key Points

- Rates of sleep apnea in women increase after menopause
- Repeated episodes of hypoxemia and increased sympathetic response can contribute to anxiety
- Sedating medications decrease muscle tone in airway and can worsen OSA
- Repeated hypoxemia and sleep fragmentation contributes to short term memory problems and word finding difficulties
- OSA is typically worse during REM sleep
- OSA increases/causes nocturia
- Rhythmic movements of sleep can be a self soothing tool for some
  - Warrants treatment/is a disorder if causing harm or poor sleep

Case: Ms. Oxy

Ms. Oxy is a 28 year old female treated with opioid pain medications for a Chiari malformation that causes intense headaches.

She has had a few “scary” episodes where her roommate wakes and thinks she is dead because she can’t see Ms. Oxy breathing.

Ms. Oxy notes sometimes waking with a racing heart. She requests something to help with her anxiety at night.

Case: Ms. Oxy
Key Points

- Brain injuries or malformations can affect the sleep wake circuitry and breathing centers in the brainstem
- Opioid medications decrease respiratory drive during sleep
  - Brain forgets to send a signal to lungs to breathe
- Decreased capacity to arouse when hypoxemic
- Concurrent use of benzodiazapines and narcotic medications are a “double whammy”
  - Increased OSA risk from loss of muscle tone
  - Central sleep apnea from blocking mu receptors

Case: Mr. Stumper

Mr. Stumper is a 43 year old male with trisomy 21, hypertension and diabetes, presenting for follow up.

He recently started a third antihypertensive agent and increased his long acting insulin.

His blood pressure and diabetes are still poorly controlled.

He has had difficulties with medication compliance in the past, and you suspect that he is not taking his medications as directed.

When asked about this, he becomes very upset an leaves the office, tearful when noting that he is always the bad guy.

He hates wearing his glasses and his carers do not think he would use PAP therapy

Case: Mr. Stumper
Key Points

- OSA increases risk of hypertension four fold
  - OSA prevents nocturnal dipping
    - Blood pressure usually drops 10-20% during sleep
- OSA causes insulin resistance due to stress response
  - Also true in non-diabetics
- Use of PAP therapy may be a challenge but also worth pursuing with a tailored approach
  - Educate patient and carers of expected benefits
  - Problem solve together
  - Set realistic goals

Case: Annie Antsy

Annie Antsy is a non-verbal 13 year old female who has recently been having agitation at bed time.

She recently started menstruating

She has always been a “picky” eater

She was started on a mirtazapine to help her sleep, which seemed to make things even worse

Case: Annie Antsy
Key Points

- Restless legs can manifest as behavioral issues, especially in those not able to communicate
- Iron deficiency is a cause of restless legs
- Medications, especially antidepressants can cause restless legs
  - 30% of people on mirtazapine get RLS symptoms

Strategies to Improve Insomnia in Adults with Neurodevelopmental Disorders

- **Stimulus control therapy** (view bed and bedroom as a sleep stimulus);
- **Sleep restriction** (restrict time spent in bed to consolidate sleep and enhance sleep quality);
- **Relaxation training** (decrease arousal and anxiety)
- **Circadian rhythm entrainment** (reinforce or reset circadian biologic clock using chronotherapy and/or light)
- **Cognitive behavior therapy** (combination of behavioral and cognitive therapies listed above).

- Level of intellectual functioning and motivation in patient (and caregivers) influence treatment choices and possibilities.

Range of Treatment Strategies for Insomnia in Adults with NDDs

- Motivation and degree of intellectual impairment;
- Willingness of patient, caregivers, and/or staff influence choices;
- However, can succeed if pursued.

Optimal scheduling;

Stimulus control;

Sleep Hygiene;

Relaxation exercise;

Imagery;

Light therapy.

Goal: Efficient Consolidated Sleep

Modify bedtimes by progressive adjustment of bed and daytime napping to achieve most efficient and consolidate sleep/wake pattern.

Sleep restriction: restrict time in bed (TIB) at night to estimated sleep duration and gradually increasing TIB once patient sleeps thru;

Gradually shorten daytime naps, providing stimulating alternatives to napping;

Avoid sleep deprivation when trying to improve bedtime schedules.

Stimulus Control Therapy

- ✓Relax before bedtime, avoid going to bed worried or angry; Use bedroom only for sleep (and intimacy);
- ✓Remove all electronic devices from bedroom; Do not read, watch TV, eat or worry in bed;
- ✓Go to bed only when tired and sleepy;
- ✓Get up at same time every morning;
- ✓Do not nap during day and try not to fall asleep anywhere else but in bed;
- ✓If unable to fall asleep within 20 minutes in bed, get up, go to another room with lights dim and do something relaxing sedentary, return to bed when sleepy.
- ✓If return to bed and again can’t sleep, leave bedroom again; repeat as needed throughout night even after awakenings.

Stimulus Control Therapy Value

- **Indication:** chronic difficulty falling and/or staying asleep;
- **Rationale:** maladaptive association of bed/bedroom with wakefulness; breakdown of healthy association of bed/bedroom with rapid-onset well-consolidated sleep;
- **Mode of action:** To break the cycle, patient must not spend time wide awake in bed or bedroom; associate bedroom = sleep;
- **Efficacy:** Most effective component of CBT-I; can be effective stand-alone therapy for many insomnia sufferer

Combating Patient Excuses and Resistance to Stimulus Control

Complaint	Responses and Solutions
If I get up out of bed, I'll become more alert and sleep even less if I stayed in bed trying to sleep	Less sleep, more drive to sleep next day increasing chance of better sleep next night; Change mindset, acceptance vs. frustration SCT = establish new conditioned response to set your mind/body for better sleep in long run.
I want to stay in my warm comfortable bed.	Have a blanket/robe nearby; Plan where you will go and set up with pillows, blankets, candles; what to do there (e.g. watch a particular TV show, magazine, crafts, massage device/heating pad)

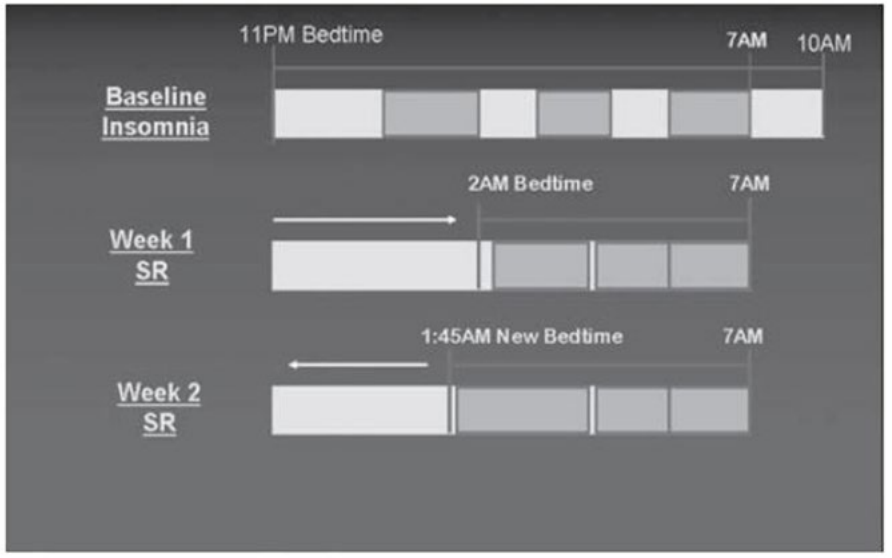
Sleep Restriction

- **Determine average total sleep time per 24 hours:**
  - Obtain and review sleep diary (± actigraphy) to determine average total sleep time (TST) per 24 hours
  - Calculate 24 hour sleep time;
- **Initial sleep restriction prescription:**
  - Time in Bed (TIB) = Total Sleep Time (TST) + 15 min for 1 week.
  - BUT a minimum TIB of 4-5 hours.

Sleep Restriction Instructions

1. Your bedtime is _____.
2. Set your alarm and get up at the same time every morning, regardless of how much sleep you got during the night. Your wake time is _____.
3. Do not nap during the day.*

* In cases where sleepiness might cause harm to self or others, go ahead and nap, go to bed earlier, sleep in, etc. In elderly, scheduling a nap might be beneficial, but try to limit to 30 minutes (and track this!).



White boxes: wake

Dark boxes: sleep

Perlis et al. Cognitive Behavioral Treatment of Insomnia: A Session-by-Session Guide. 2005

Sleep Restriction Titration Rules

- Creates a mild state of sleep deprivation
  - Promotes more rapid sleep onset and more efficient sleep
- Based on average of sleep efficiency
  - Time asleep/ Time in bed
    - >90%, increase bedtime by 15 minutes;
    - If = 85-89% same TIB;
    - If <85%: decrease time in bed by 15-30 minutes.
    - If elder, increase TIB by 15 minutes if >80% and allow 30-minute nap;
- As sleep consolidation improves, time in bed and asleep increases;

Sleep Restriction Therapy (SRT)

- **Indication:** difficulty falling/staying asleep;
- **Rationale:** chronic insomnia sufferers unable to get appropriate amount of consolidated sleep at appropriate time of day; can benefit from hard reset of their sleep schedule;
- **Mode of action:** Limit amount of time person can spend in bed to their average sleep time;
- **Efficacy:** very effective, critical component of CBT-I; generally not done alone.

Combating Arguments for Sleep Restriction

Patient/Carer Complains	Your Responses
I already don't get enough sleep, how will staying in bed even less help?	TIB is matched to TST, not restricting you to less than average sleep time; Just commit for 1 week; Short-term pain for long term gain Educate regarding sleep drive, rationale
I usually sleep in when have a really bad night, if I can't I'll be a wreck.	Sleepiness can help you sleep the next night If sleepy to point where risk to self or others take a nap but set alarm; Use caffeine in moderation Focus on what you can control: staying awake till bedtime and getting up same day each morning Short term pain for long term gain
I can't stay up until my bedtime	Finger out stimulating activities to keep you awake; avoid sleep inducing activites.

Sleep Compression:
Gentler Form of Sleep Restriction Therapy

Methods:

1) Determine difference between average total sleep time (TST) and time in bed (TIB) over 1-2 weeks;
2) Example: TIB 6.1 h; TST 4.5 h = 96 minutes;
3) 96 min/5 weeks = 20 minutes/week;
4) Reduce TIB by 20 minutes each week;
5) Track sleep efficiency after each week and adjust TIB appropriately.

- **Indication:** difficulty falling and/or staying asleep; alternative for those who cannot tolerate sudden reduction in total sleep time;
- **Rationale:** chronic insomnia sufferers unable to get healthy amount of consolidated sleep at appropriate time of day; may benefit from slow reset of their sleep schedule;
- **Mode of action:** gradually limits amount of time person can spend in bed to their average sleep time;
- **Efficacy:** works more slowly than sleep restriction but equally effective.

Cognitive Behavioral and Behavioral Treatment Strategies Used to Treat Insomnia in Children with ASD and/or NDD

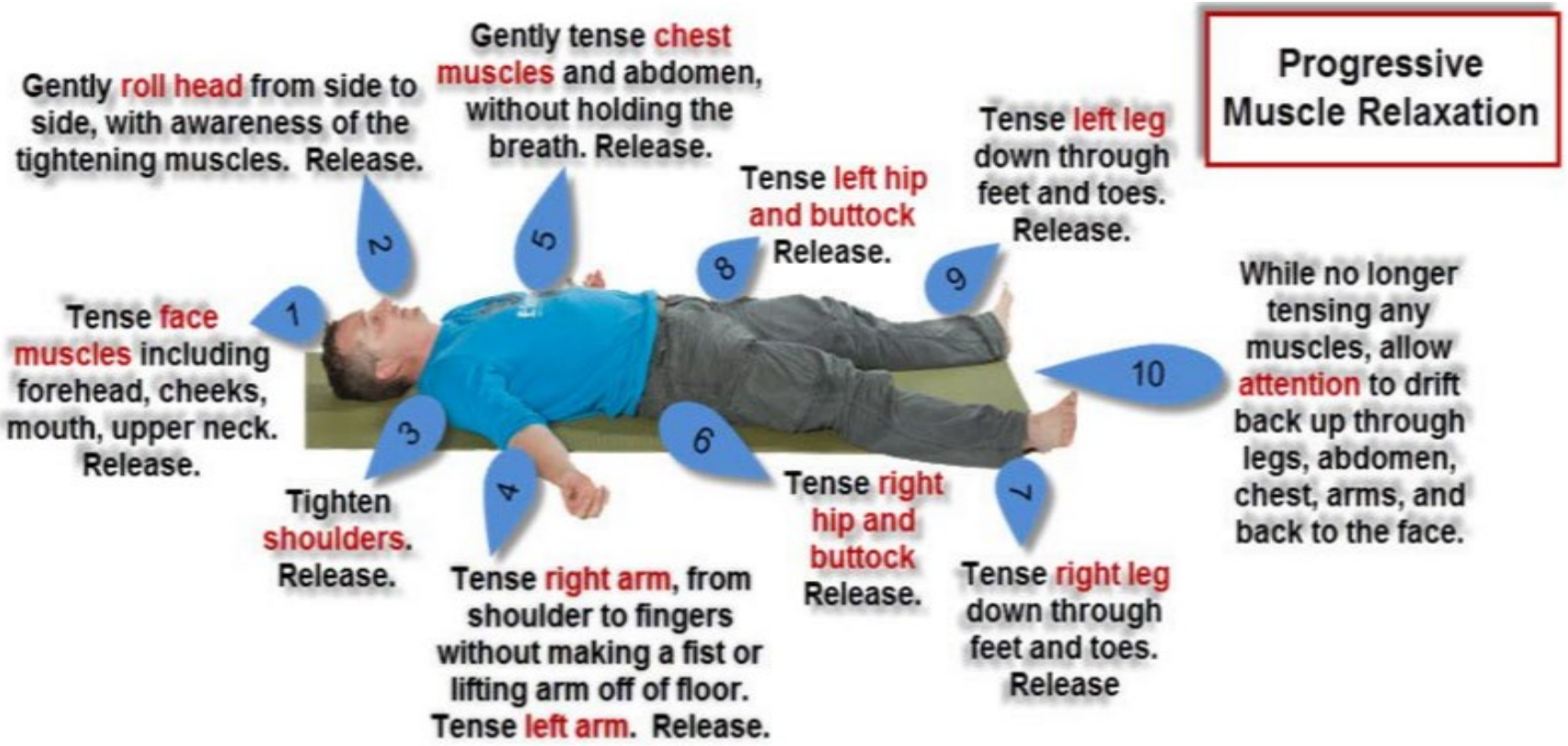
Parents serve as active agents of change and are taught to:
Create a quality sleeping environment:
Dark, quiet, nonstimulating, and perceived as safe (dim nightlight if needed)
Eliminate visual and auditory stimuli (turn off electronics)
Adjust ambient temperature if necessary (cool better than warm)
Develop a successful bedtime routine, which is consistently followed and tailored to the developmental age and abilities of the child
Promote self-soothing skills that allow the child to fall and return to sleep on own
Maintain a consistent sleep/wake schedule:
Put to bed and get them up same time every day
Difficulty falling asleep:
Temporarily delay child's bedtimes by calculating the average sleep-onset time during baseline, then adding 30 min (e.g., average sleep onset 9:30 p.m. during baseline, initial bedtime 10 p.m.)
Once child falls asleep within 15–20 min, gradually move the bedtime earlier in 30-min increments as long as the child continues to fall asleep quickly until reaching a parent-determined goal bedtime (e.g., 8:30 p.m.)
Do not allow the child to make up for lost sleep by going to bed earlier or sleeping later
Parent–child interactions:
Parents avoid responding to the child's disruptive bedtime behaviors (crying, tantrums, calling out, or leaving the bedroom)
Parents who have difficulty ignoring the child can use the Excuse-Me Drill; parents periodically check on the child, but only when the child is showing desired behaviors (calm, quiet, and in bed). This is repeated for nighttime awakenings
A bedroom pass (allowing only one bedroom exit per night) is often useful

Grigg-Damberger and Ralls. Current Opinion in Pul Med 2013;19(6)616-25.

Relaxation Therapy

- Progressive muscle relaxation
- Guided imagery
- Diaphragmatic breathing

- **Indication:** insomnia suffers who view their insomnia as “inability to relax”;
- **Rationale:** chronic insomnia can arise from overactive sympathetic nervous system with hyperarousal;
- **Effectiveness:** effective as adjunct for anxiety-related problems.



- While inhaling, contract one muscle group for 5-10 seconds, then exhale and suddenly release the tension in that muscle group.
- Relax for 10-20 seconds, then move on to the next muscle group.
- While releasing the muscle tension, try to focus on the changes you feel when the muscle group is relaxed. Image release of tension including stressful feelings are flowing out of your body as you relax each muscle group.
- Gradually work your way up the body contracting and relaxing muscle groups.

Slow Breathing to Calm Self

- Breathe in slowly for 5 seconds then hold your breath for 5-10 seconds then breathe out for 5-10 seconds;
- Repeat until you feel calm;
- Pay attention to feeling of air filling your lungs, hold you breath a little longer than an ordinary breath; and pretend you are breathing out through a straw.

Using Visual Imagery to Relax

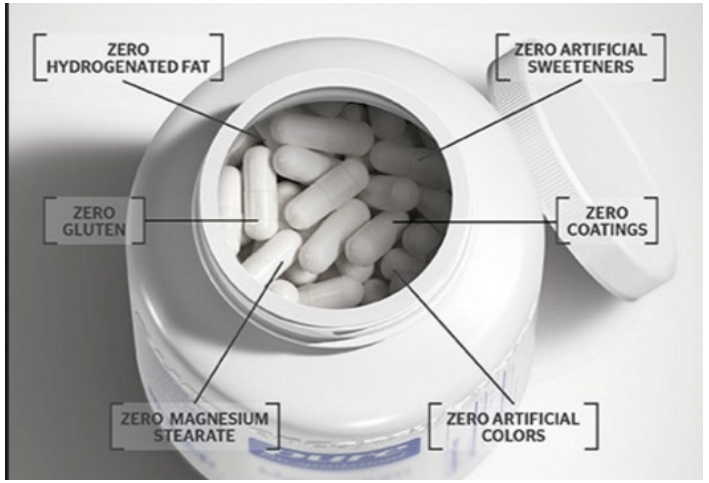
- Think about some of your favorite and least favorite places.
- Paint a picture of the calming place in your mind: Imagine every little detail. Go through each of your senses and imagine what you would experience in your relaxing place.
- Example: You are on a tropical beach…
  - Sight: Sun high in sky and you're surrounded by white sand. There's no one else around. The water is a greenish-blue and waves are calmly rolling in from the ocean.
  - Sound: You can hear the deep pounding and splashing of the waves. There are seagulls somewhere in the background.
  - Touch: The sun is warm on your back, but a breeze cools you down just enough. You can feel sand moving between my toes.
  - Taste: You have a glass of lemonade that's sweet, tart, and refreshing;
  - Smell: You can smell the fresh ocean air, full of salt and calming aromas.

Intelligent Melatonin Use

- Will reduce sleep onset time by 30-40 minutes;
- Unlikely to lessen nocturnal awakenings;
- Adverse effects minimal
- Start with a low dose (0.5 mg);
- Suspect slow metabolizers: take breaks
- Late DLMO predicts increased success;
- No evidence slow release superior to fast release.

Melatonin

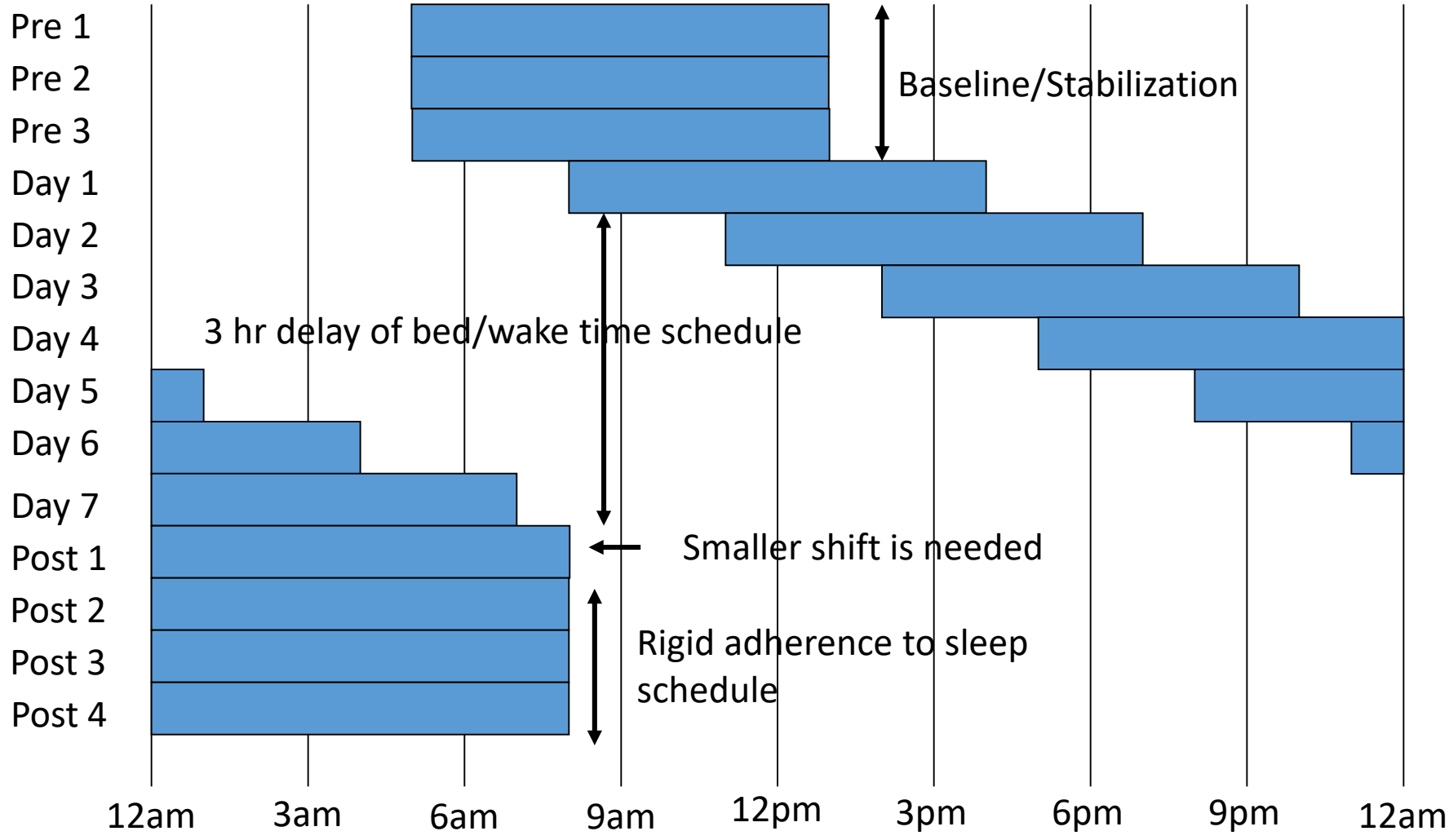
- Circadian phase dependent hypnotic;
- Only hormone available in US without a prescription;
- 1994 US Dietary Health and Education Act allows it to be sold as a dietary supplement;
- No confirmed reports of toxicity or overdose;
- Best to get “pharmaceutical grade
- Exogenous melatonin has 45 minute half life unless sustained release:
- If use as hypnotic give 15-30 min before bed.



Melatonin

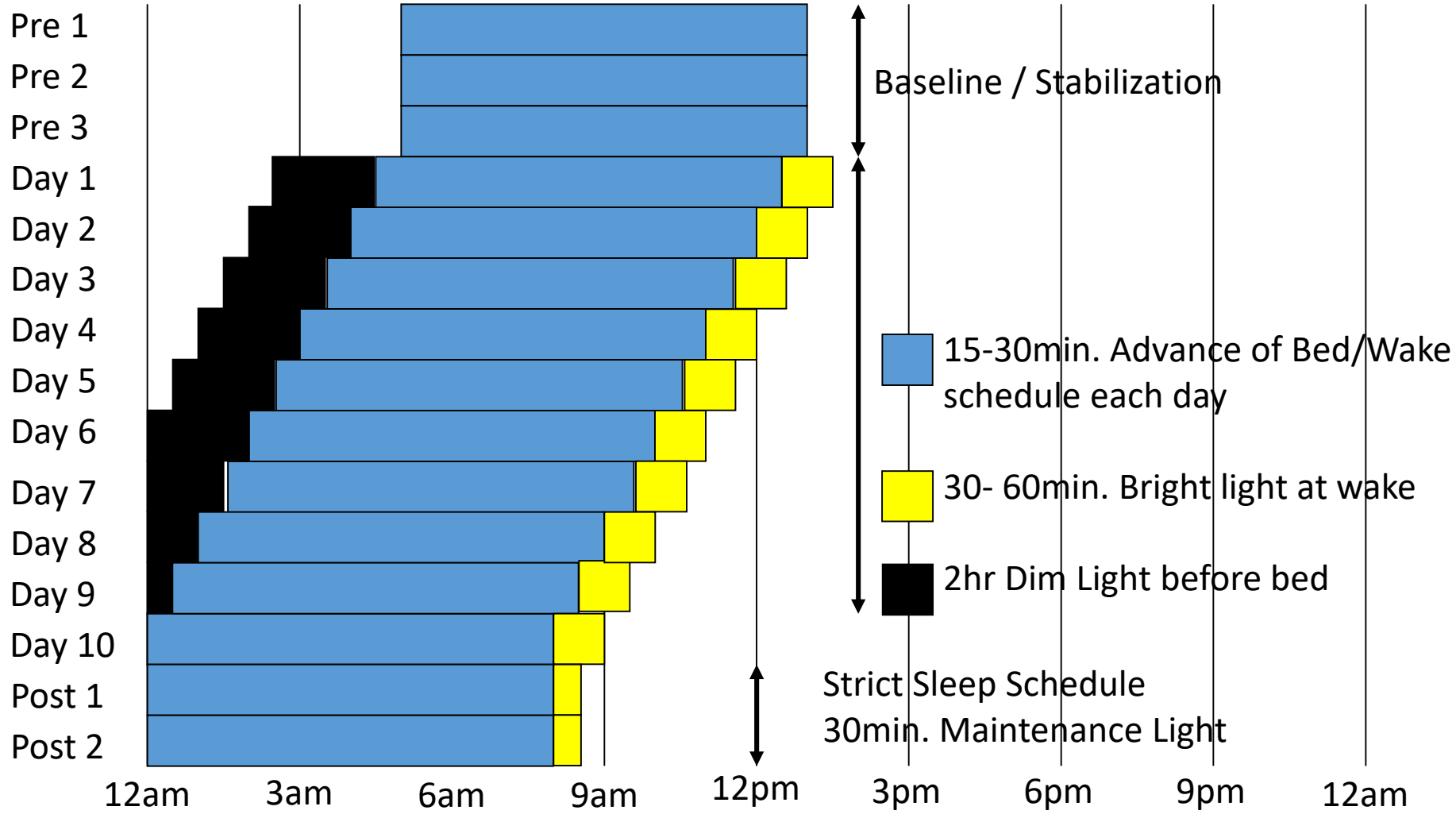
- Current recommendations see no additional benefit in doses greater than 3 mg.
  - 0.5-5 mg shows dose response curve; >5 mg may less effective.
  - 0.5 mg approximates natural melatonin concentration in the blood (unknown concentration in the brain).
- Phase shifting is slow with melatonin (15 min per day)
- Chronic administration may be needed;
- Wrong timing → wrong shift.

Chronotherapy for Delayed Sleep/Wake Disorder

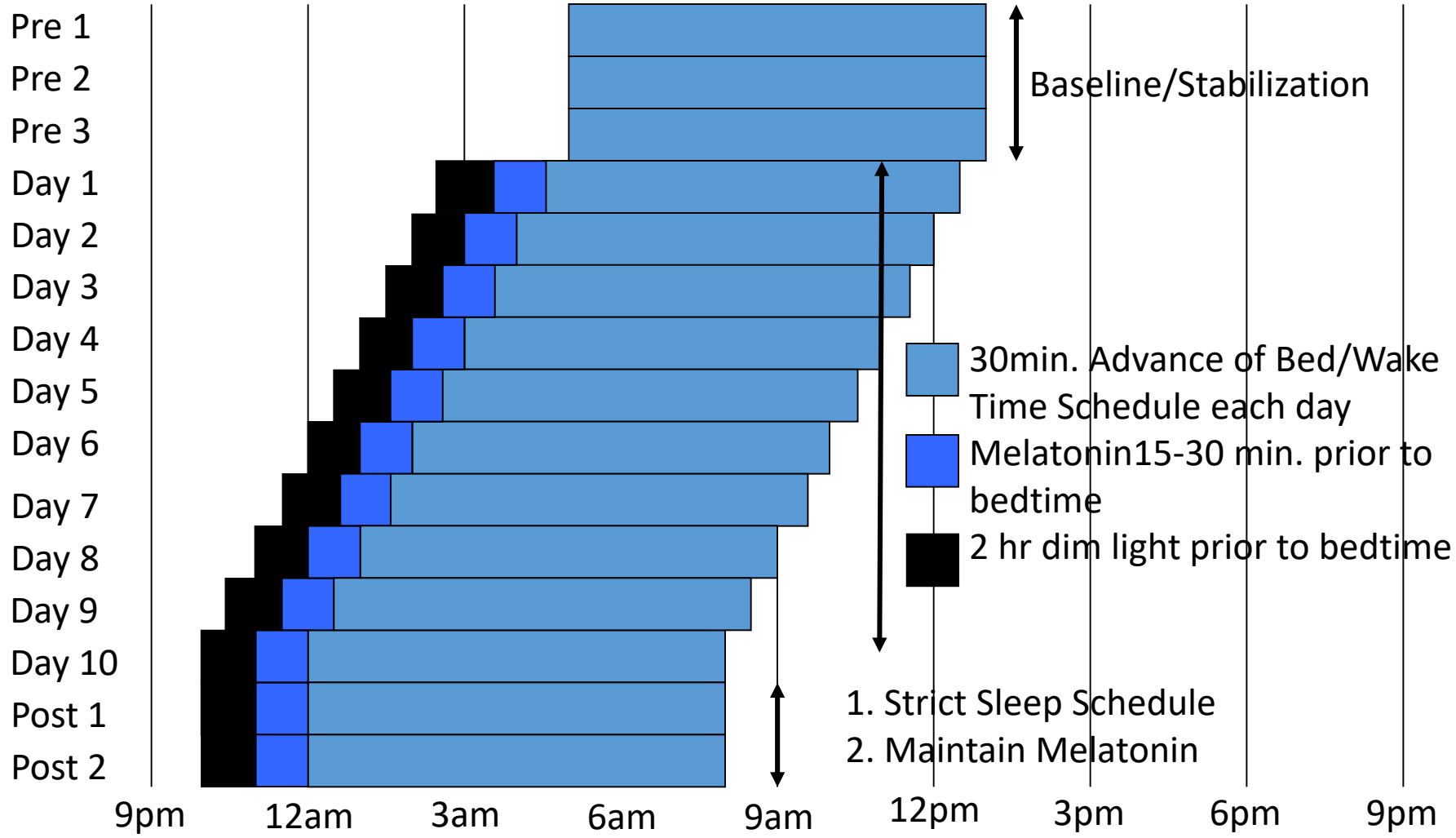


 Modified from Czeisler et al., Sleep, 1982

Phototherapy for Delayed Sleep Phase



Melatonin For Delayed Sleep-Wake Disorder



Overall Summary

- People with NDD/ID have more sleep disturbance and worse symptoms than the general population
- Sleep disorders are underdiagnosed and under-treated
- Identifying sleep problems is the first step

  "do you consider that you have sleep problems?"
- Addressing poor sleep reduces health risks and improves quality of life
- Tailoring interventions to each patient and carer is important for success

Sleep Well (And Don’t Let Bed Bugs Bite)

Questions?

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