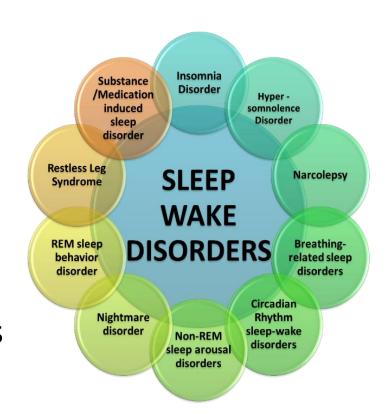


Objectives

- Name three common sleep problems in people with I/DD
- Learn about screening tools for sleep problems
- Understand how we evaluate people for sleep disorders.
- Learn about interventions to improve sleep quality

Common Sleep Disorders in People with NDD/ID

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



BMI > 35



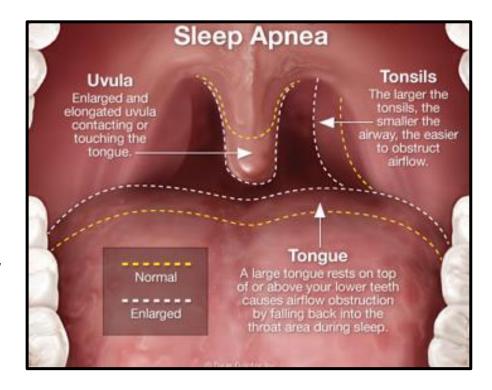
Neck Circumference

- > 16 in women
- > 17 in men



Crowded Oropharynx

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







- 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



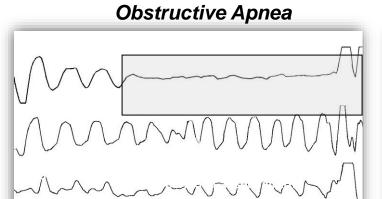
Screening Tools for Obstructive Sleep Apnea (OSA) in Adults with NDD/ID

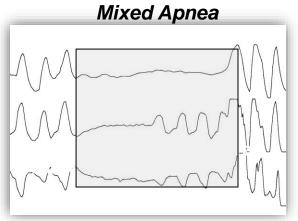
GASP Screen for OSA

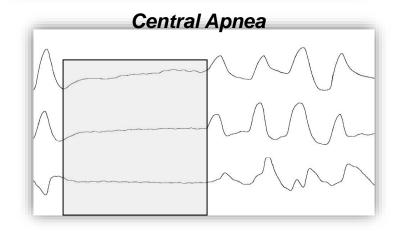
- During the night do you?
 - G gasp or choke?
 - A stop breathing?
 - S snore loudly
 - P perspire (sweat);
- Do you have trouble sleeping?
- Is your sleep refreshing?
- Are you sleepy in the day?
- Take naps?

Stop-Bang Questionnaire

1. Snoring Do you snore loudly (louder than talking or loud enough to be heard through closed doors)?	Yes/No
Tired Do you often feel tired, fatigued, or sleepy during daytime?	Yes/No
3. O bserved apnea Has anyone observed you stop breathing during your sleep?	Yes/No
4. Blood p ressure Do you have or are you treated for high blood pressure?	Yes/No
5. B Ml more than 35 kg/m ² ?	Yes/No
6. A ge Age over 50 yr old?	Yes/No
7. N eck circumference Neck circumference greater than 40 cm?	Yes/No
8. G ender Gender male?	Yes/No
High risk of OSA: answering yes to three or more items Low risk of OSA: answering yes to fewer than three items	



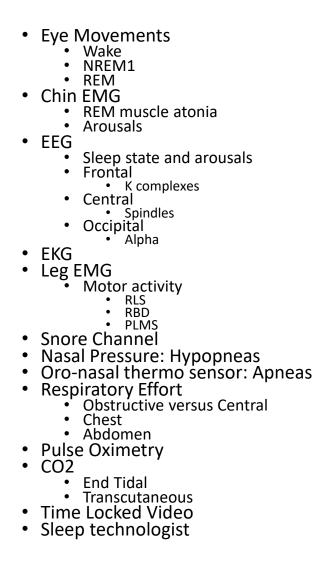




We classify sleep apnea in a PSG based upon INSPIRATORY effort during absent airflow

Evaluating for Sleep Apnea

Polysomnography





Polysomnography made more comfortable

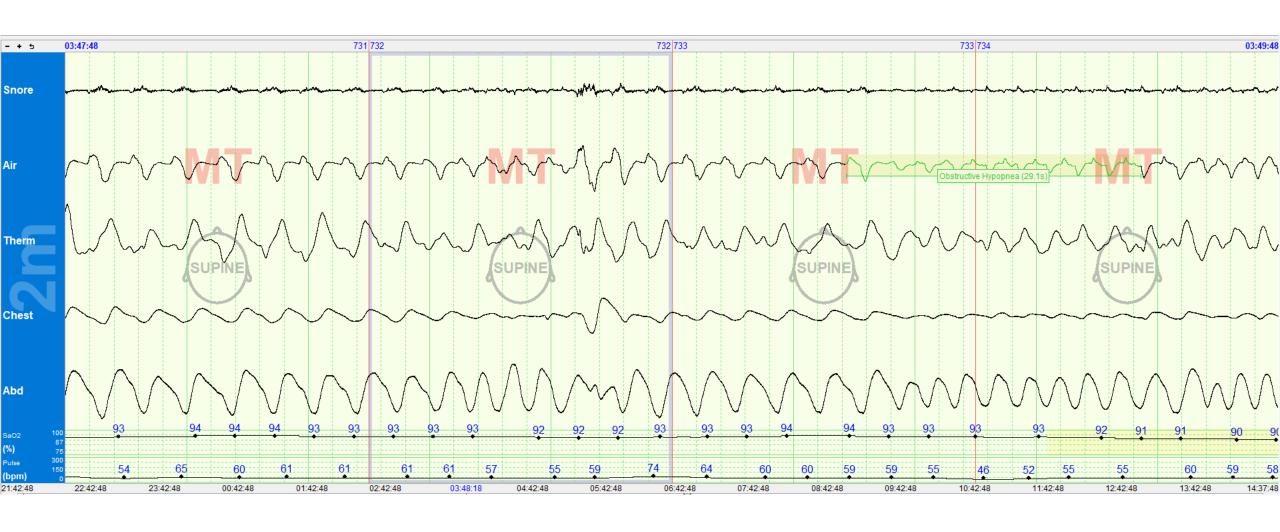
- Expectations
 - Sleep Lab Tour
 - Brochure and Video about sleep studies
 - Hands on look at wires, masks
 - Mask and air pressure desensitization
- Caregiver
 - Stay with patient in the night
- Routine
 - Bring any objects/medications that are used nightly
- Registered Polysomnographic Technologists
 - Provide education
 - Can work on a 1:1 basis with I/DD

Wired Up and Ready to "Sleep"

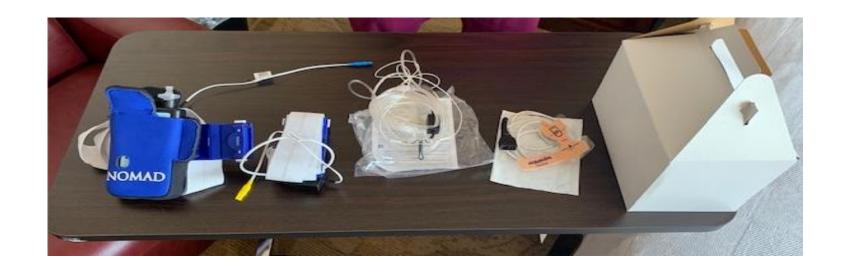




Home Sleep Apnea Test



HOME SLEEP APNEA TEST

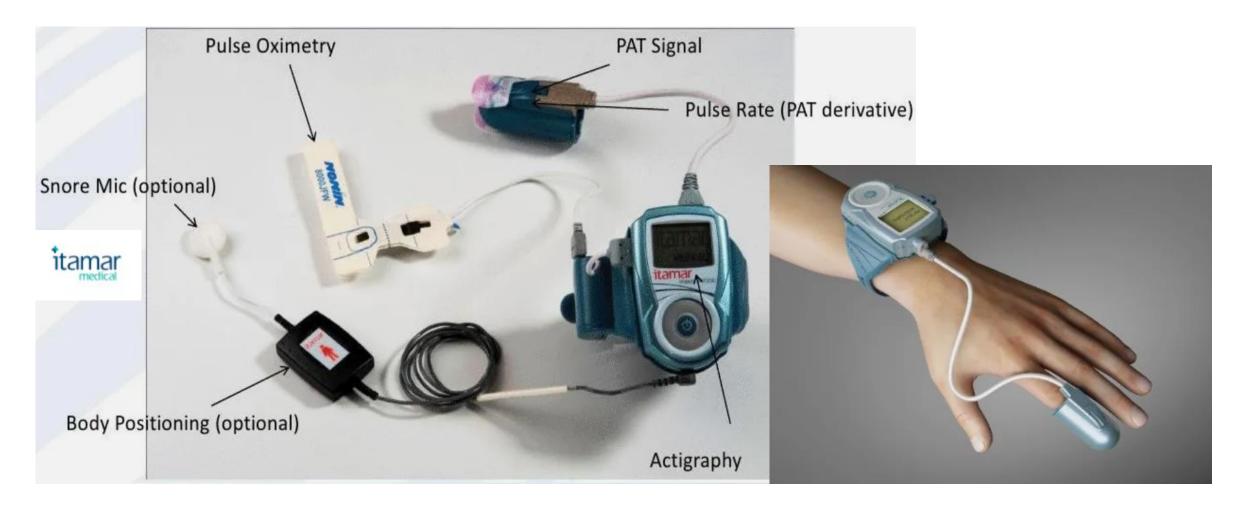


Everything you need will be in the box

Complete look



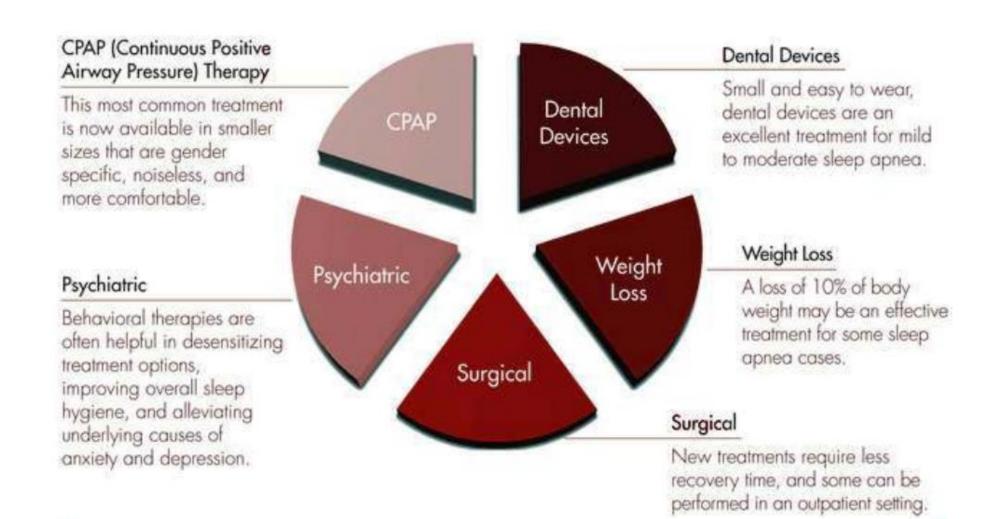
WatchPAT



Oximetry Can Offer Clues ...



Treatment for OSA



So Many Masks to Try!

☐ Full face(fits over you mouth)



□Nasal Mask (over your nose)



□Pillows (fits on your nostrils)



Inspired? Or a different Remede?

- Inspire: Hypoglossal nerve stimulator for Obstructive sleep apnea
- Remede: Diaphragm Pacer for Central Sleep Apnea
- Neither will address hypoxemia or hypoxentilation*

Inspire

- Opens airway by advancing tongue during inspiration
- Drug induced sleep endoscopy to see if airway has anterior/posterior collapse
 - Not approved for concentric collapse
- Moderate to severe obstructive sleep apnea
 - Cannot have > 25% central sleep apnea events
- BMI < 40*

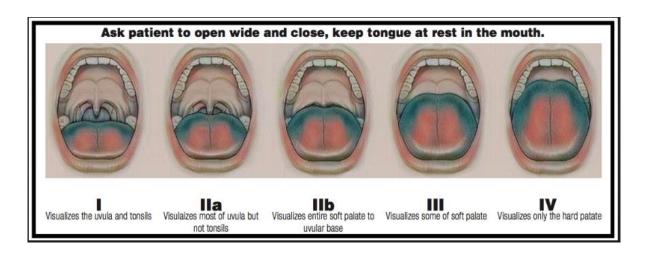
How it Works

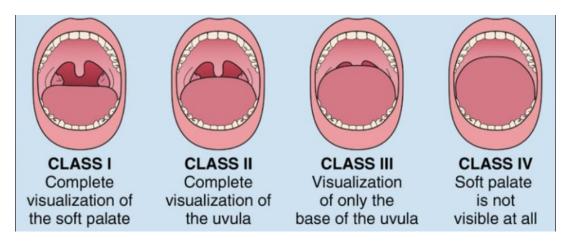
Inspire works inside your body while you sleep. It's a small device placed during a same-day, outpatient procedure. When you're ready for bed, simply click the remote to turn Inspire on. While you sleep, Inspire opens your airway, allowing you to breathe normally and sleep peacefully.



Not as Inspired

- BMI of 32 35 had lower odds of responding compared to BMI < 32
- Supine sleeping reduces response
- Friedman tongue position IV and Mallampati IIII/IV less responsive





Remede

- Used for moderate to severe primary central sleep apnea
- Need to have > 50% central breathing events

Short Term (1-3 months):



It is typically recommended that you wear a sling to keep your arm in a low position for the first 48 hours. It is important to minimize arm movement immediately after your procedure.

Long Term:



Avoid high powered electromagnetic fields. Electrical and magnetic equipment such as arc welding units, induction furnaces and stoves, resistance welders, radio or microwave transmitters, linear power amplifiers have the possibility of interacting with the remedē System.



Limit physical activities prone to falling.
Falling can cause the device and/or the leads to move or get pulled out of place and can require a second procedure.



Avoid raising your arm above your shoulder.

Raising your arm on the side of your implant can cause the leads to get pulled out of place and require a second procedure.



Maintain distances when using a cell phone. Cell phones can interact with the device.

- Do not place them on the chest area on the same side as the remedē device
- Maintain at least 10 inches between your cell phone and the remede device
- Hold the phone to the ear farthest from the device

Inspired Case Report

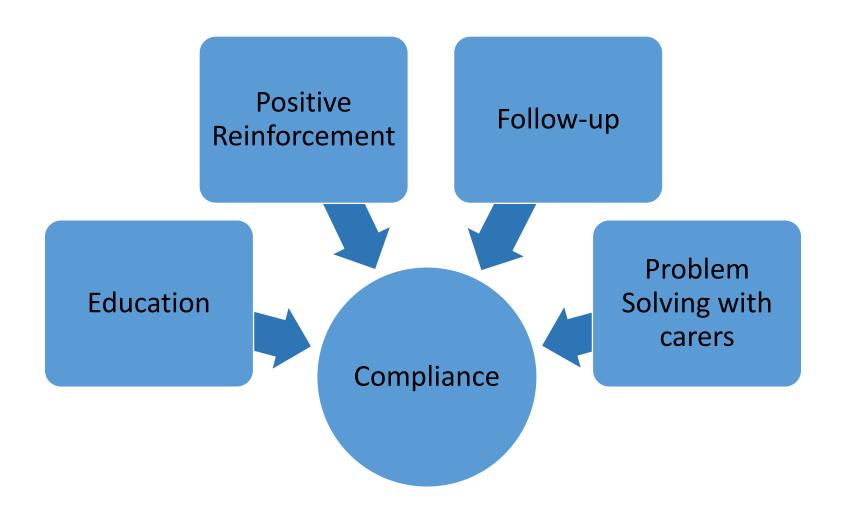
- 28 year old male with hypotonia and developmental delay due to Cerebral Palsy
- Was having 112 breathing events per hour of sleep
- Failed PAP therapy
- Inspire reduced breathing events to 12 per hour and improved ventilation and oxygenation

Positional Treatment of OSA and Improving Nasal Congestion

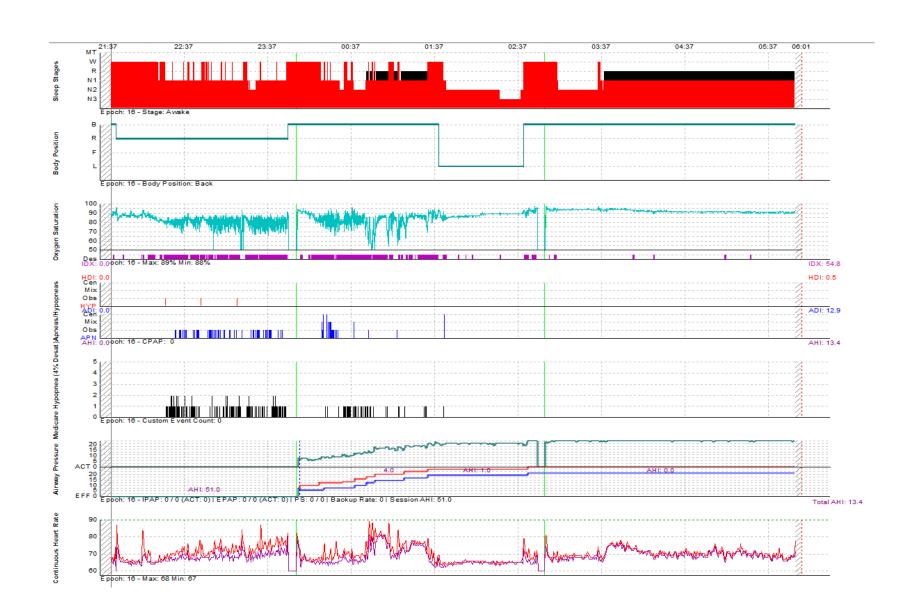
- Sleep Apnea is usually worse when laying supine
- Sleeping in a lateral sleep position helps keep tongue out of the way
- Sleeping in a reclined position reduces airway obstruction
- Using nasal saline can reduce nasal congestion that wakes breathing worse
- Nasal steroids and or allergy medications reduce nasal congestion from allergies to improve breathing

- PAP therapy is still the gold standard for sleep apnea
- PAP can also help with ventilation and oxygenation while other OSA treatments do not

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

Snoring Tired Observed Pressure

Age Neck Gender

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 -like a car motor", which makes Mr. Willi feel persecuted.

What Sleep Problems do you identify?

What is the first step for evaluation?

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. Bicarbonate level of > 27 may be a clue
 - 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.

What Sleep Problems do you identify?

What is the first step for evaluation?

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.

What Sleep Problems do you identify?

What is the first step for evaluation?

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

What Sleep Problems do you identify?

What can we do about trying to treat his sleep apnea?

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

Common Sleep Problems in Developmentally Delayed Individuals

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

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

Circadian Rhythm = Process C

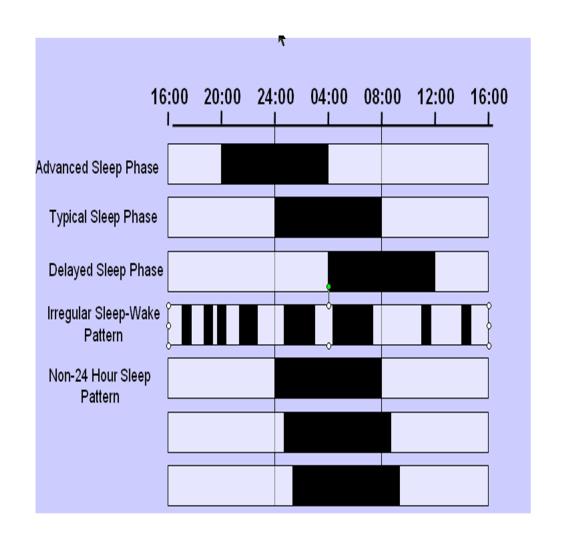
Homeostatic sleep drive or "sleep pressure" = Process S

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

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



Screening for Circadian Rhythm Disorders

- What time is naturally preferred to go to bed/get up?
- Is it easier to go to bed later and get up later?
- If they could sleep when they preferred would they have trouble sleeping?
- Have they always kept these hours? Since childhood?
- Is there anyone in the family who prefers to go to bed really late or get up really early?
- Does bedtime seem to get later and later over a week?

Sleep Diary

It is virtually impossible to treat insomnia or circadian rhythm disorder 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

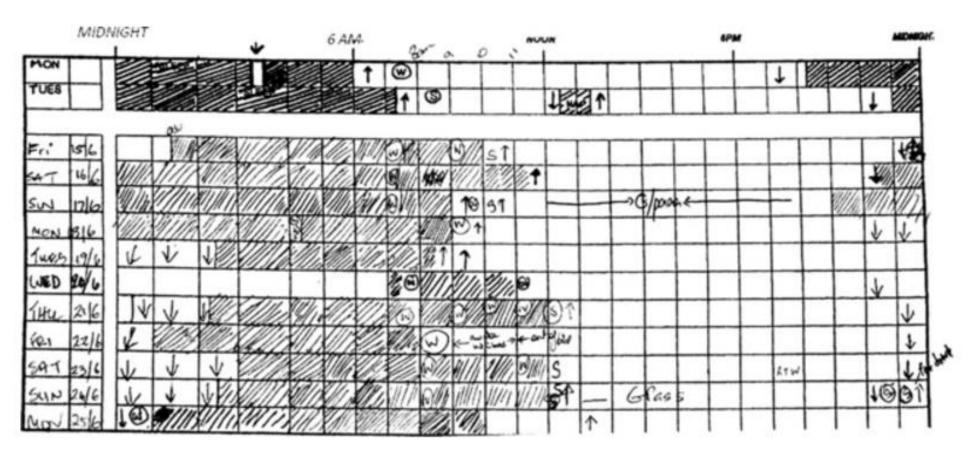
Write the date, day of the week, and type of day: Work, School, Day Off, or Vacation.

- 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 (I) to show when you go to bed. Shade in the box that shows when you think you fell asleep.
- Shade in all the boxes that show when you are asleep at night or when you take a nap during the day.
- Leave boxes unshaded to show when you wake up at night and when you are awake during the day.

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.

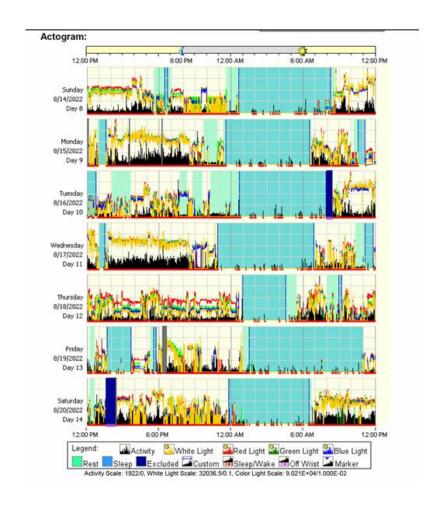
Today's Date		Type of Day Work, School, Off, Vacation		1PM		60	4	ID.	6PM	7	80	6	10	11PM	Midnight	1AM	2	8	4	10	6AM	7	80	6	10	11AM	
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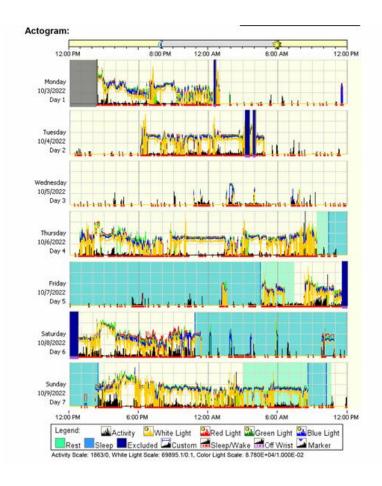
Sleep Diary Late Bed and Wake Times

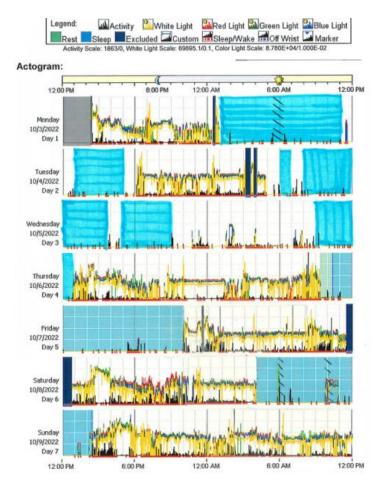


 Obstructive sleep apnea (OSA) is probably only sleep disorder in which a sleep diary not so helpful.

Actigraphy can help... sometimes







What is the Hype about Chronotype?

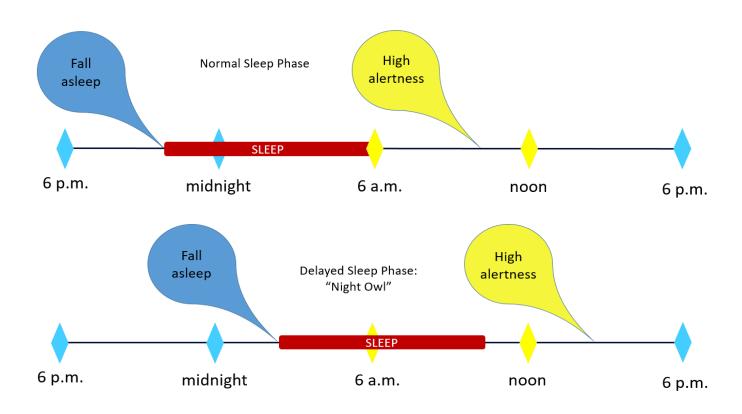
Chronotype= inter-individual differences in the phenotypic expression of behavioral outputs regulated by the circadian system

LAI	ARE YOU A RK or an OV	VL?					
	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

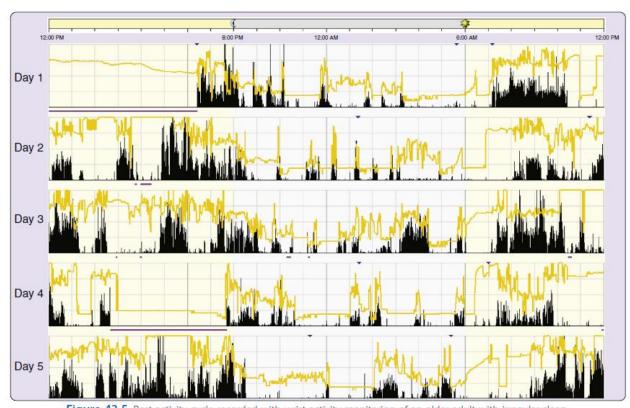
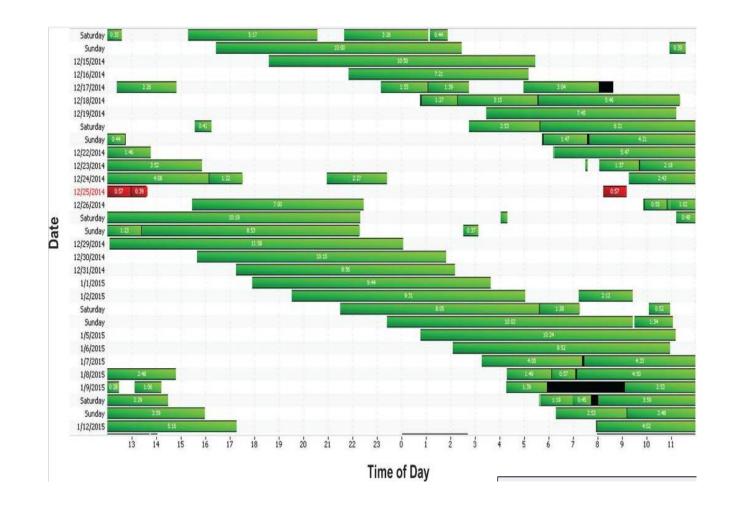


Figure 43.5 Rest-activity cycle recorded with wrist-activity monitoring of an older adult with irregular sleep-wake rhythm disorder. The *black bars* indicate activity levels, and the *yellow bars* indicate the level of ambient light exposure recorded at the nondominant wrist. Note the lack of a discernible circadian sleep and wake rhythm. Sleep is characterized by nocturnal fragmentation and multiple short periods of sleep and wake across the entire 24-hour day.

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: Luna

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

What is her primary sleep issue?

- A) Initial Insomnia
- B) Anxiety about returning to school
- C) Circadian Sleep phase delay
- D) Poor sleep hygiene
- E) Bipolar Disorder

Where do you start to help with sleep?

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

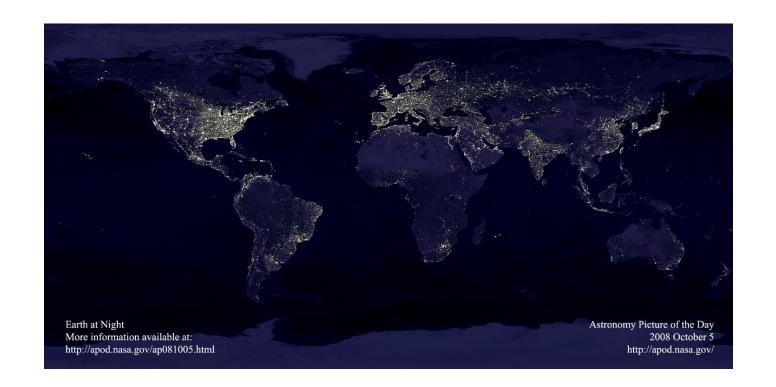
- Ask permission to share information
- Help the patient and/or carer understand the effects of lifestyle and environment on sleep

Brainstorm

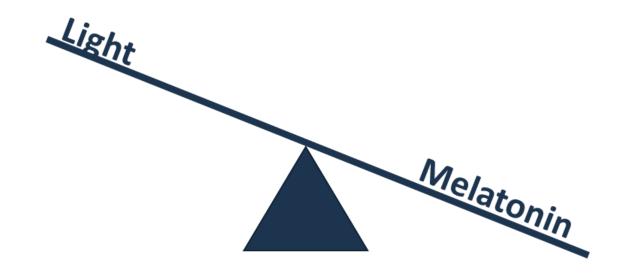
- Even modest adaptations to daily routine and sleeping environment can be of benefit
- Interventions need to be tailored to the person and carer

Improving Sleep in People with NDD/ID

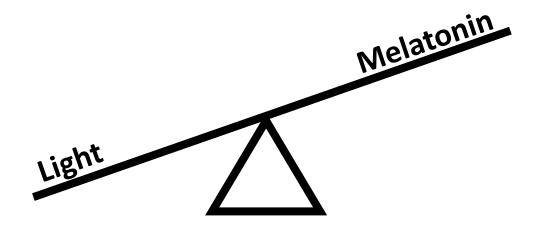
- Biological interventions
 - Treat underlying contributors
 - Pharmacological and alternative treatments
- Social-behavioral interventions
 - Sleep Hygiene
 - Exercise-related
- Educational and behavioral interventions well accepted and favorably received



See the Light About Avoiding Light Before Sleep



Turn Off Electronics at Least 30 Minutes Before Going To Bed



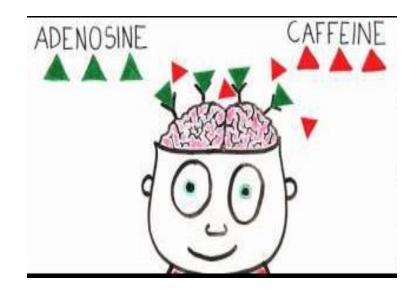
Cool Down For Better Sleep

- 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

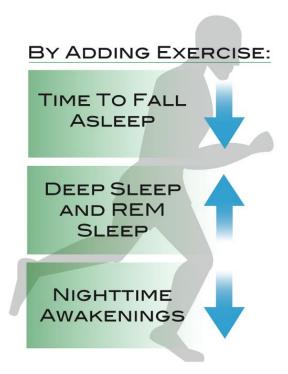


Caffeine Helps With Fatigue But Interferes With Sleep

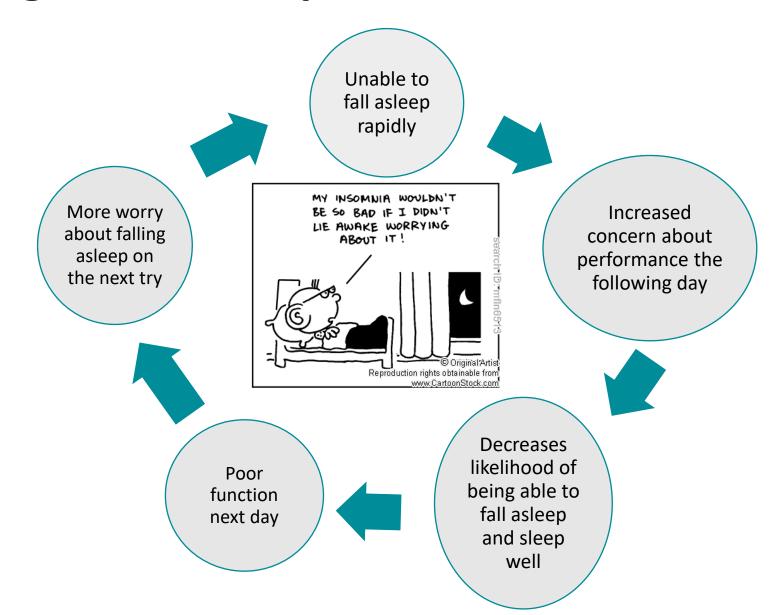
- Caffeine blocks adenosine
 - More adenosine builds up the longer you are awake
- Adenosine signals the brain about becoming sleepy
- Adenosine is washed out of the brain during sleep
- Caffeine stays in your system for 10-12 hours
 - Tricks the brain into ignoring sleepiness even when you are tired



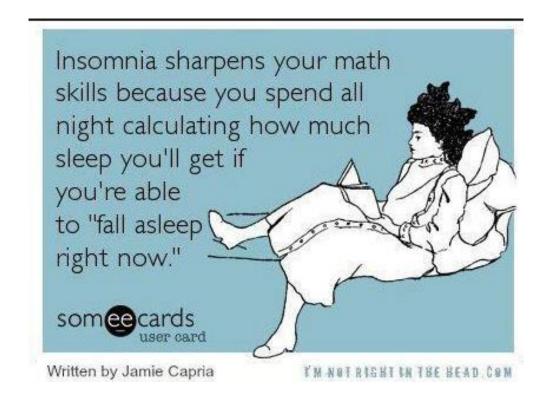
Increase Activity to Improve Sleep And Decrease Fatigue



Worrying About Sleep Makes It Harder To Sleep



Avoid Looking At The Time When Having Trouble Sleeping



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).

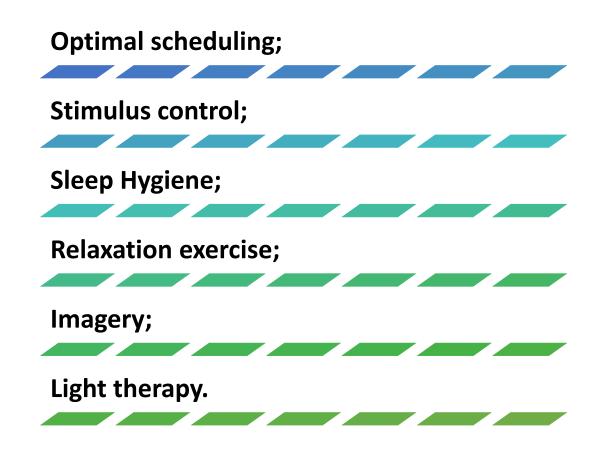


 Level of intellectual functioning and motivation in patient (and caregivers) influence treatment choices and possibilities.



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.



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 standalone therapy for many insomnia sufferer

Combating Patient Excuses and Resistance to Stimulus Control

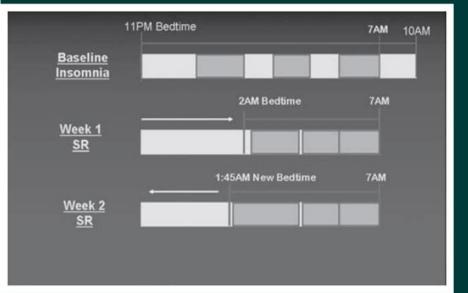
Complaint	Responses and Solutions
If I get up out of bed, I'll become more alert and sleep even less if I	Less sleep, more drive to sleep next day increasing chance of better sleep next night;
stayed in bed trying to sleep	Change mindset, acceptance vs. frustration SCT = establish new conditioned response 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 (<u>+</u>
 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%, move bedtime 15 minutes earlier;
 - 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.

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.
- 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

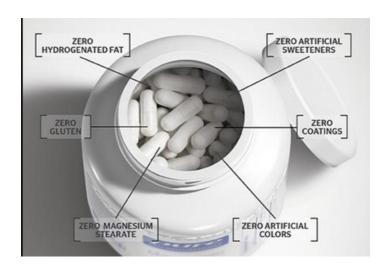
- Will reduce sleep onset time by 30-40 minutes;
- Unlikely to lessen nocturnal awakenings;
- Adverse effects minimal
- Start with a low dose (0.5 mg);
- Suspect slow metabolizers: take breaks
- Late dim light melatonin onet (DLMO) predicts increased success;
- No evidence slow release superior to fast 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 used as hypnotic give 15-30 min before bed.
- If used for chronobiotic for delayed sleep wake cycle give 5 hours before usual bedtime (at diner time, 0.5-3 mg)

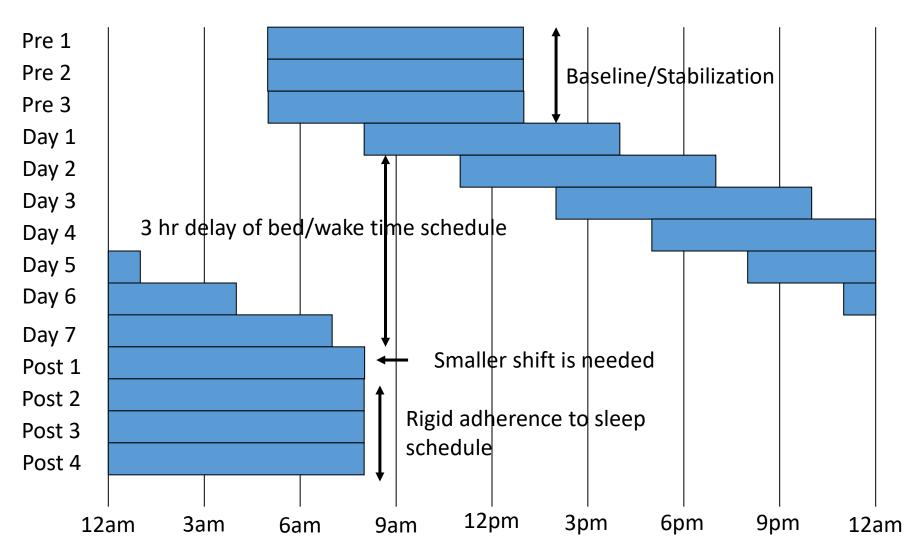




Melatonin for Circadian Rhythm

- Current recommendations see no additional benefit in doses greater than 3 mg to improve sleep cycle.
 - 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



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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