

# Sleep Problems In Adults With Neurodevelopmental Disorders

Madeleine Grigg-Damberger MD

Professor of Neurology

Continuum of Care Symposia

November 9, 2016 10:00 to 11:00 AM



I have no conflicts of interest related to this talk and subject

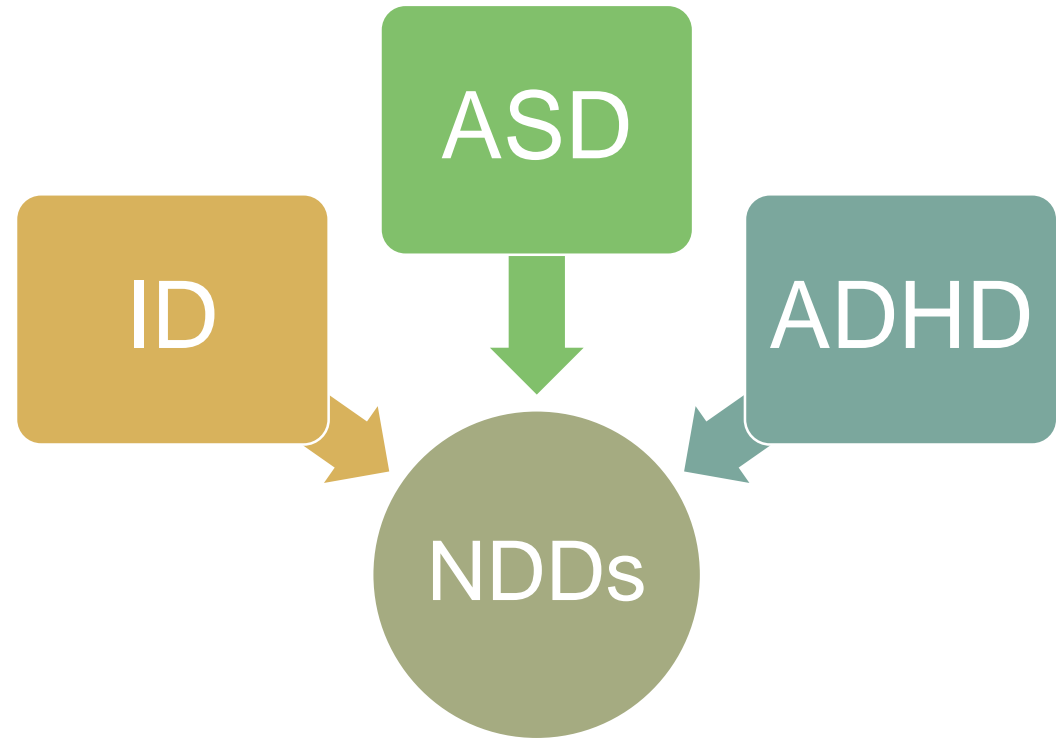
# Overview of Talk

- Sleep disorders are common in adults with neurodevelopmental disorders with/without concomitant intellectual disability (ID), autism spectrum disorder (ASD), and/or attention deficit/hyperactivity disorder (ADHD);
- Screening tools for identifying sleep problems in adults with NDD;
- Evaluating and treating insomnia in adults with NDD.



# Common Comorbidities in People with Neurodevelopmental Disorders (NDD)

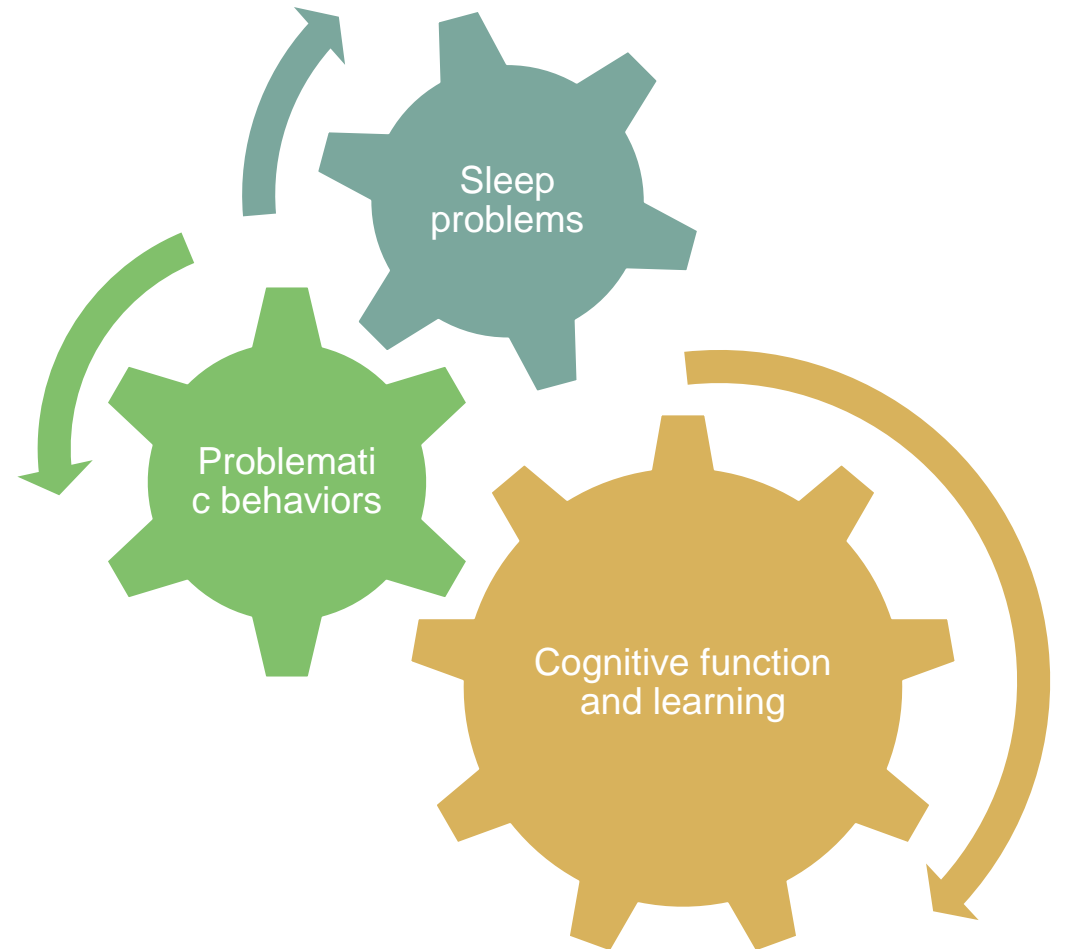
- NDDs are group of disorders caused by changes in early brain development → cognitive and behavioral changes in motor, sensory, speech and/or language systems.
- NDDs 1-2% of general population.



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

# 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 Neurodevelopmental Disorders

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

Attention deficits

Memory problems

Impaired cognitive function

Compulsive behavior

Impaired social interactions

Abnormal sensory processing

# Sleep Disorders in Adults with NDD Same as Those Seen in Neurotypical Adults

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

However, sleep problems in people with NDD compared to general population are:



# Sleep Disturbances Common in Adults with NDD, ID, ASD, and/or ADHD

- **Study #1**: Sleep/wake complaints among 205 community-living adults with ID:
  - **27%** Difficulty falling asleep;
  - **56%** Nocturnal awakenings;
  - **15%** Sleep disordered breathing.



- Insomnia (difficulty falling or staying asleep) most common complaint.



# Study #2: Sleep Patterns in Adults with High-Functioning Autism Spectrum Disorders (HF-ASD)



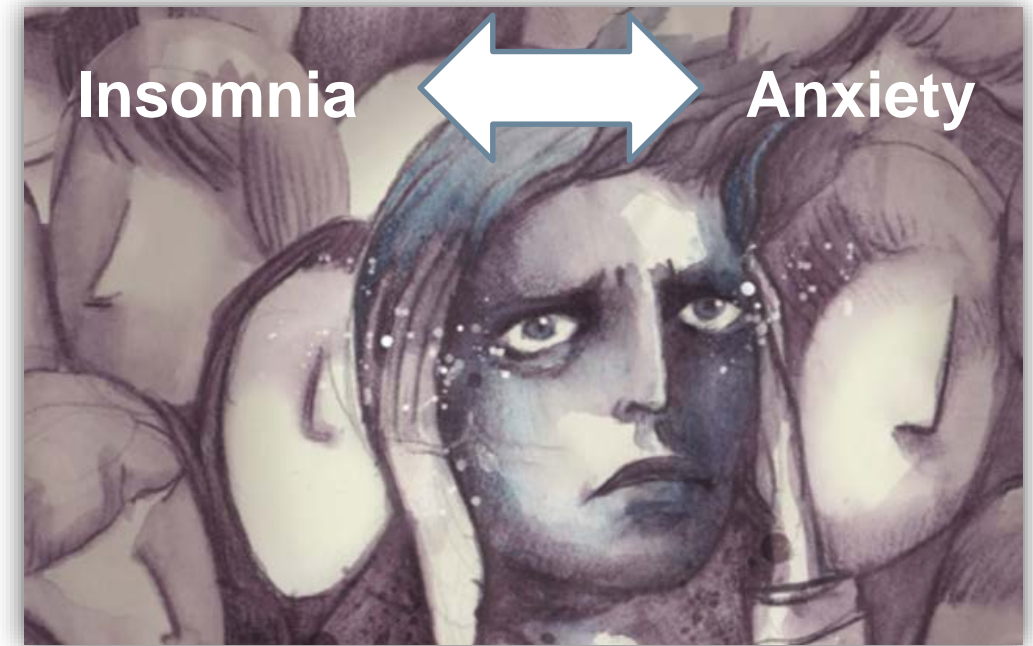
- Case-control cross-sectional study of **36** adults with HF-ASD and 36 age, IQ- and sex-matched neurotypical (NT) adults.

- Adults with HF-ASD had significantly more general sleep disturbances compared to NT:
  - HF-ASD more likely to meet criteria for insomnia (28% HF-ASD vs 6% NT);
- HF-ASD adults had:
  - 1) Higher scores on validated sleep questionnaire (PSQI);
  - 2) Longer time to fall asleep (sleep latency) on actigraphy;
  - 3) Poorer sleep efficiency, more fragmented sleep, and longer sleep latency on sleep diary.





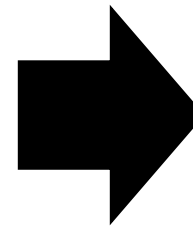
- **Study #3**: 164 (111 M, 53 F) adults with NDDs attending ASD and ADHD clinics:
  - 111 M, 53 F, 30 ASD, 98 ADHD, 34 ASD+ADHD;
  - 91% had poor sleep on Pittsburgh Sleep Quality Index (total score 5+);
  - 44% moderate/severe insomnia on Insomnia Severity Index (score 15+).



- 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.

# Case-Control PSG Studies Find Poorer Sleep Architecture More Often HF-ASD than NT Adults

	First Author, Year	Sample Size	PSG Findings
Study #1	Limoges et al. 2005	27 adolescents and adults (16-27) with HF-ASD and 78 NT adults	HF-ASD longer sleep onset latency, more nocturnal awakenings, and poorer sleep efficiency
Study #2	Tani et al. 2003	20 adults with HF-ASD and 10 NT adults	Higher percent of HF-ASD had wake after sleep onset $\geq$ 30 min compared to NT adults.
Study #3	Hare et al. 2006	16 HF-ASD and 16 NT adults	HF-ASD longer sleep latency, more fragmented sleep, poorer sleep efficiency than NT adults



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



**Autistic Spectrum Disorder**



**Smith-Magenis Syndrome**



**Rett Syndrome**



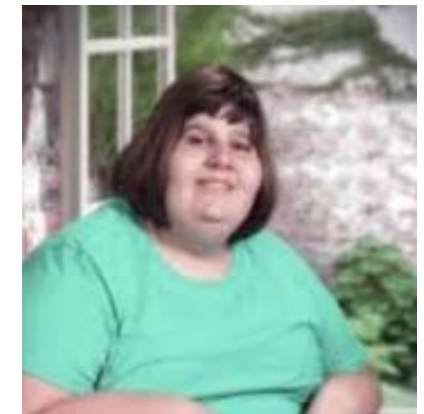
**Down Syndrome**



**Williams Syndrome**



**Fragile X Syndrome**



**Prader-Willi Syndrome**



# 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 prognathism **d**. Wounds from skin picking can be seen at any age **d**

Poisson et al. *Orphanet Journal of Rare Diseases* (2015) 10:111  
DOI 10.1186/s13023-015-0330-x

**OJRD** ORPHANET JOURNAL  
OF RARE DISEASES

**POSITION STATEMENT**

**Open Access**

## Behavioral disturbance and treatment strategies in Smith-Magenis syndrome



Alice Poisson<sup>1,2,3\*</sup>, Alain Nicolas<sup>1,4</sup>, Pierre Cochat<sup>3,5</sup>, Damien Sanlaville<sup>3,6</sup>, Caroline Rigard<sup>1,2</sup>, H el ene de Leersnyder, Patricia Franco<sup>3,7</sup>, Vincent Des Portes<sup>3,9</sup>, Patrick Edey<sup>3,6,8</sup> and Caroline Demily<sup>1,2,3</sup>

### 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, neuropsychiatrists/neurologists, somnologists, developmental and behavioral pediatricians, and speech and language therapists.

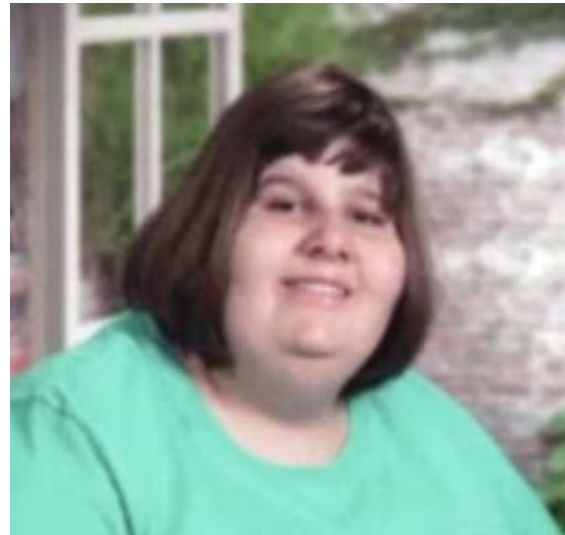


# Smith-Magenis Syndrome (SMS)

- 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.



# 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



# Myotonic Dystrophy Type 1 At Risk FOR OSA, CSA And Central Hypersomnia

- Children and adults with DM1 at risk for:
  - Obstructive and central sleep apnea;
  - Central hypersomnia;
  - Cognitive impairment making PAP adherence challenging;
  - Hypothyroidism;
  - Cardiac conduction disorder (60-times general population).

---

## RELATIVE RISKS FOR COMORBIDITIES ASSOCIATED WITH MYOTONIC DYSTROPHY: A POPULATION-BASED ANALYSIS

NICHOLAS E. JOHNSON, MD,<sup>1</sup> DIANA ABBOTT, PhD,<sup>2</sup> and LISA A. CANNON-ALBRIGHT, PhD<sup>2,3</sup>

<sup>1</sup>Department of Neurology, University of Utah School of Medicine, Salt Lake City, 30 N 1900 SOM 3E228, Utah 84132, USA

<sup>2</sup>Division of Genetic Epidemiology, Department of Internal Medicine, University of Utah School of Medicine, Salt Lake City, Utah, USA

<sup>3</sup>George E. Wahlen Department of Veterans Affairs Medical Center, Salt Lake City, Utah, USA

Accepted 7 July 2015

**ABSTRACT:** *Introduction:* A population-level relative risk assessment for comorbidities associated with myotonic dystrophy has not been performed. *Methods:* In this study we utilized

---

**Abbreviations:** DM, myotonic dystrophy; DM1, myotonic dystrophy type 1; DM2, myotonic dystrophy type 2; ICD-9, *International Classification of Diseases, 9th edition*; RR, relative risk; UPDB, Utah Population Database; UUHSC, University of Utah Health Sciences Center

**Key words:** genetic epidemiology; hypothyroidism; myotonic dystrophy; population; relative risk; sleep apnea

N.E.J. is funded by the National Institutes of Health (1K23NS091511-01) and has also received research support from the Muscular Dystrophy Association, Valerion Therapeutics, Isis Pharmaceuticals, and Biogen Idec.

**Correspondence to:** N.E. Johnson; e-mail: nicholas.johnson@hsc.utah.edu

the Utah Population Database to identify patients with myotonic dystrophy in Utah according to ICD-9 coding. Comorbidity cases listed in the medical record were compared with those of the Utah population. *Results:* Individuals with myotonic dystrophy were found to possess an increased risk of central and obstructive sleep apnea, hypothyroidism, and intellectual disability. The risk of cardiac conduction disorder is 60 times the population risk. *Conclusions:* This study provides a population-level relative risk assessment of comorbidities in myotonic dystrophy. This allows for improved counseling of patients regarding these increased risks.

*Muscle Nerve* 52: 659–661, 2015

**T**he myotonic dystrophies (DMs) are autosomal-





## Evaluating and Treating Some Common Sleep Disorders Seen in Adults with NDD



# Many Sleep Problems in Adults with NDD Can Be Treated with Teamwork

- Insomnia;
- Circadian rhythm disorders;
- Sleep apnea
- Central hypersomnia



- At least once a year screen individual for sleep problems, if positive for possible insomnia, then;
- Request patient (and/or caregiver) to complete a 2-week daily sleep log (and teach them how to do it);
- Ask them to calculate (if possible) their sleep efficiency (how much time in bed spent sleeping).



## Screening Tools For Identifying Sleep Disorders In Adults With Neurodevelopmental Disorders

# 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

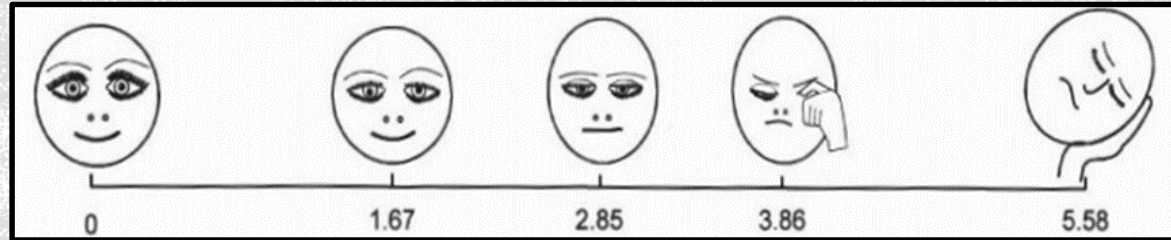
Component 1	#9 Score	C1	_____
Component 2	#2 Score (<15min (0), 16-30min (1), 31-60 min (2), >60min (3)) + #5a Score (if sum is equal 0=0; 1-2=1; 3-4=2; 5-6=3)	C2	_____
Component 3	#4 Score (>7 (0), 6-7 (1), 5-6 (2), <5 (3))	C3	_____
Component 4	(total # of hours asleep) / (total # of hours in bed) x 100 >85%=0, 75%-84%=1, 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	<input type="checkbox"/>
2. Watching TV	<input type="checkbox"/>
3. Sitting inactive in a public place (e.g., theater or meeting)	<input type="checkbox"/>
4. As a passenger in a car for an hour without a break	<input type="checkbox"/>
5. Lying down to rest in the afternoon when able	<input type="checkbox"/>
6. Sitting and talking to someone	<input type="checkbox"/>
7. Sitting quietly after a lunch without alcohol	<input type="checkbox"/>
8. In a car while stopped for a few minutes in traffic	<input type="checkbox"/>

Abnormal ESS score >10.

Name: \_\_\_\_\_ Date: \_\_\_/\_\_\_/\_\_\_ Hospital No: \_\_\_\_\_ Date of Birth: \_\_\_/\_\_\_/\_\_\_

In contrast to just feeling tired, how likely are you to doze off or fall asleep in the following situations? Even if you have not done some of these things recently, try to work out how they would affect you. Use the following scale to choose the most appropriate number for each situation.

Situation <input checked="" type="checkbox"/> Please tick box	0 No chance of dozing	1 Slight chance	2 Moderate chance	3 Definitely would doze
Sitting and reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sitting inactive in a public place (e.g. Theatre or a meeting)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
As a passenger in a car for an hour without a break	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lying down to rest in the afternoon when circumstances permit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sitting and talking to someone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sitting quietly after lunch without alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In a car, while stopped for a few minutes in traffic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 a measure of willingness to pursue treatment.

Can use sleep apps (Sleep Cycle or Sleep Bot)

**TWO WEEK SLEEP DIARY**

**INSTRUCTIONS:**

- 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.
- Put a line (|) 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.

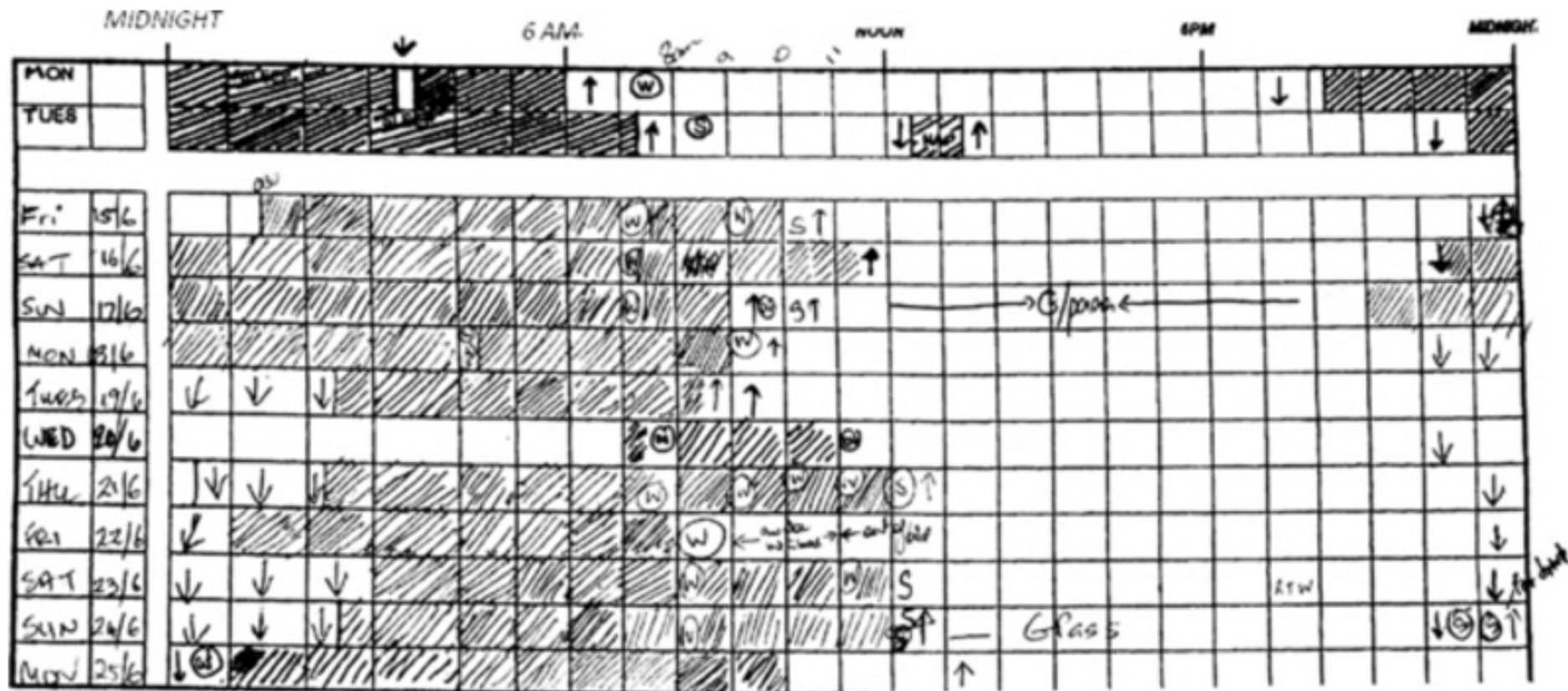
**SAMPLE ENTRY BELOW:** *On a Monday when I worked, I jogged on my lunch break at 1 PM, had a glass of wine with dinner at 6 PM, fell asleep watching TV from 7 to 8 PM, went to bed at 10:30 PM, fell asleep around Midnight, woke up and couldn't get back to sleep at about 4 AM, went back to sleep from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

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.

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

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



# Stop-Bang Questionnaire Screening for Obstructive Sleep Apnea in Adults

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







# Treating Insomnia in People with Neurodevelopmental Disorders



# Insomnia in Adults with NDDs Began in Childhood and Have Persisted



# Insomnia

## ■ **Clinical features of insomnia:**

- Trouble falling asleep (>30 minutes);
- Frequent and/or prolonged nocturnal awakenings;
- Early morning awakenings with difficulty returning to sleep;
- Poor sleep quality;
- Poor sleep efficiency;
- Cognitive arousal;

## ■ **Severity of insomnia judged by:**

- Frequency, intensity and duration of sleep difficulties;
- Impact on daytime functioning, mood and quality of life.

## ■ **Cultural issues of insomnia:**

- How long to sleep at night and/or to nap;
- Is insomnia a disease, complaint, disorder, symptom, and/or finding;
- Is insomnia due to physical and/psychiatric problems, too much work, exhaustion,



# Most Common Sleep Problems in Adults 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.



# Neurobehavior Factors Which Can Contribute to Insomnia in NDD

Unhealthy sleep practices and patterns

Hypersensitivity to environmental stimuli

Hyperarousal or difficulty with self-regulation

Repetitive thoughts/behaviors at bedtime interfere with settling

Inability to benefit from social or communicative cues about sleep



# Factors Which Can Contribute to Insomnia in Adults 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

# 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

Avoid sleep deprivation when trying to improve bedtime schedules.



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;



# 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)



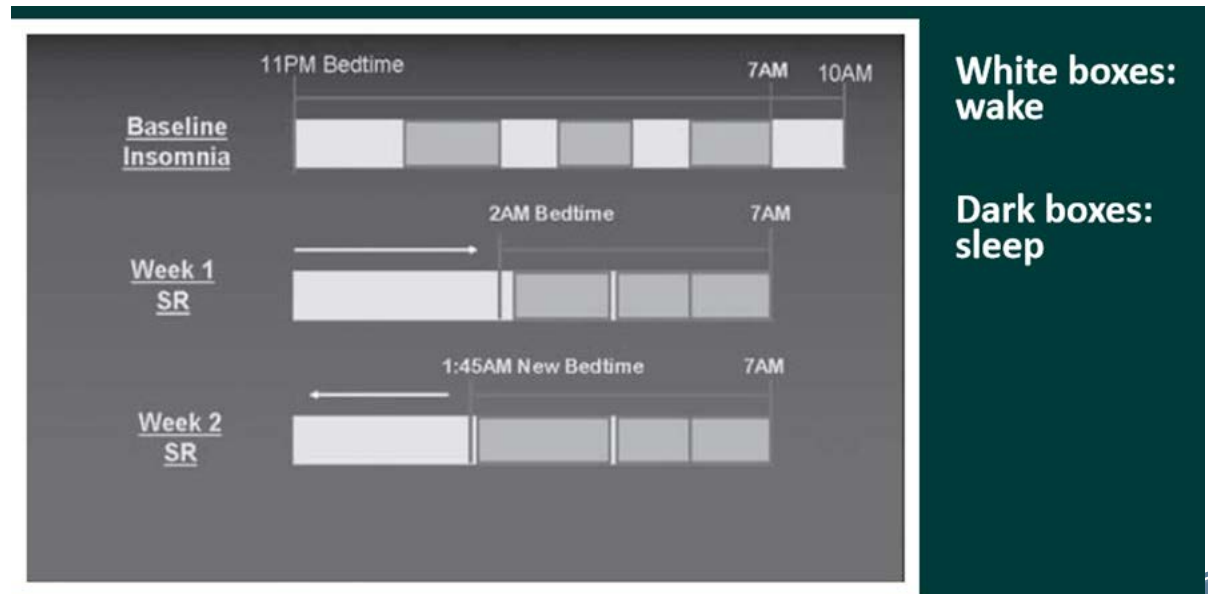
# Sleep Restriction

- **Determine average total sleep time per 24 hours:**
  - Obtain and review sleep diary ( $\pm$  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!).



# Sleep Restriction Titration Rules

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



# 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.



# Sleep Hygiene Education

- Avoid caffeine 4-6 hours before bedtime;
- Regular exercise in morning/afternoon; avoid exercise before bedtime;
- Avoid alcohol, nicotine, large/heavy meals, excessive fluid, spicy/acidic foods close to bedtime;
- Create a sleep-friendly environment: dark, cool, quiet bedroom with a comfortable bed;
- Get up same time every morning regardless of amount of sleep obtained; Avoid daytime naps;
- Get exposure to natural light every morning.





# 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:**

- Not effective stand-alone therapy for chronic insomnia, but effective with combined with stimulus control and sleep restriction therapy.



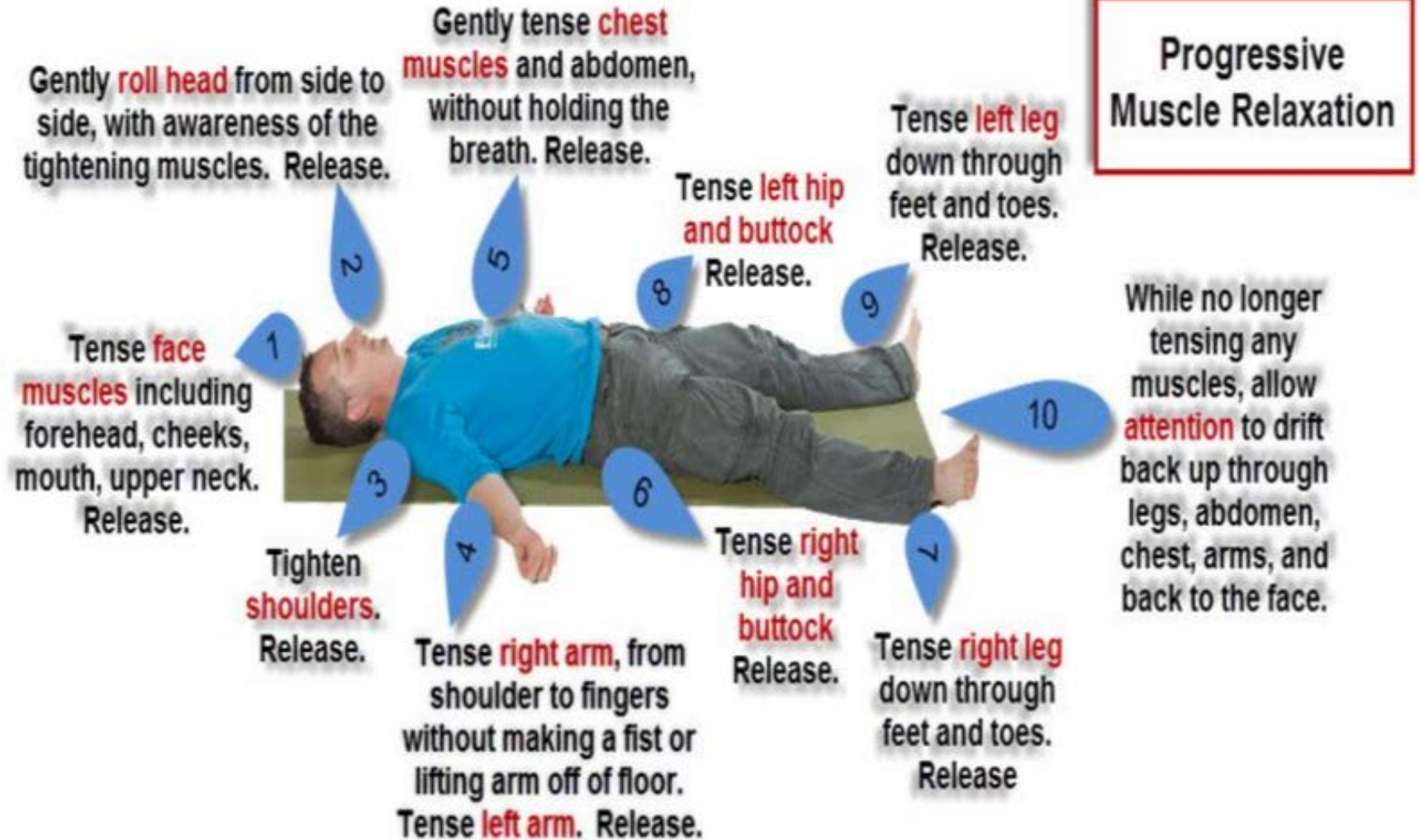
# Relaxation Therapy



- Progressive muscle relaxation
  - Guided imagery
  - Diaphragmatic breathing.
- **Indication:** insomnia sufferers 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.



# 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.





**Sleep Well (And Don't Let Bed Bugs Bite)**

# References on Sleep Problems in Adults with Intellectual Disability

1. Brylewski J and Wiggs L. J Intellectual Disability Rese 1999;43:504-12;
2. Gunning MJ and Espie CA J Intellectual Disability Research 2003;47(3):191-202.
3. Harvey MT et al. Journal of Positive Behavior Interventions 2003;5.
4. Galli-Carminati G et al. Swiss Med Weekly 2009;139"19-20:293-6
5. Malow BA et al. Sleep 2006;29(12):1563-71.
6. Haqrvey M. International J Develop Neuroscience 2002;20(3-5):443-8;
7. Luiselli JK et al. Mental Retardation 2005;43(6):414-20;
8. Diomedi M Brain and Development 1999;21(8):548-53.

