



Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

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Circadian Rhythm Sleep Disorders and Narcolepsy

by

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Overview

- Introduction
- Circadian Rhythm Sleep Disorders
 - Definitions
 - DSPS
 - Non-24
 - Treatment and Issues
- Relationships to Narcolepsy
- Circadian Sleep Disorders Network



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Circadian Rhythms

- 24 hours 10 minutes on average
- *Entrained* to 24 hours (*zeitgebers*)
- Suprachiasmatic nucleus (SCN) – the master clock
- ipRGC cells (intrinsically photosensitive Retinal Ganglion Cells)



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Circadian Rhythm Sleep Disorders

- Definition
- Complaints
 - Insomnia
 - Excessive daytime sleepiness
- Coordination with other circadian rhythms
- Inflexibility



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Circadian Sleep Disorder Subtypes*

- Delayed Sleep-Phase Syndrome
- Non-24-Hour Sleep-Wake Disorder
- Advanced Sleep-Phase Syndrome
- Irregular Sleep-Wake Pattern
- Shift Work Sleep Disorder
- Jet Lag Syndrome

* From *The International Classification of Sleep Disorders, Revised* (ICSD-R)



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Definition of DSPS

from *The International Classification of Sleep Disorders, Revised* (ICSD-R):

- Sleep-onset and wake times that are intractably later than desired
- Actual sleep-onset times at nearly the same daily clock hour
- Little or no reported difficulty in maintaining sleep once sleep has begun
- Extreme difficulty awakening at the desired time in the morning, and
- A relatively severe to absolute inability to advance the sleep phase to earlier hours by enforcing conventional sleep and wake times.



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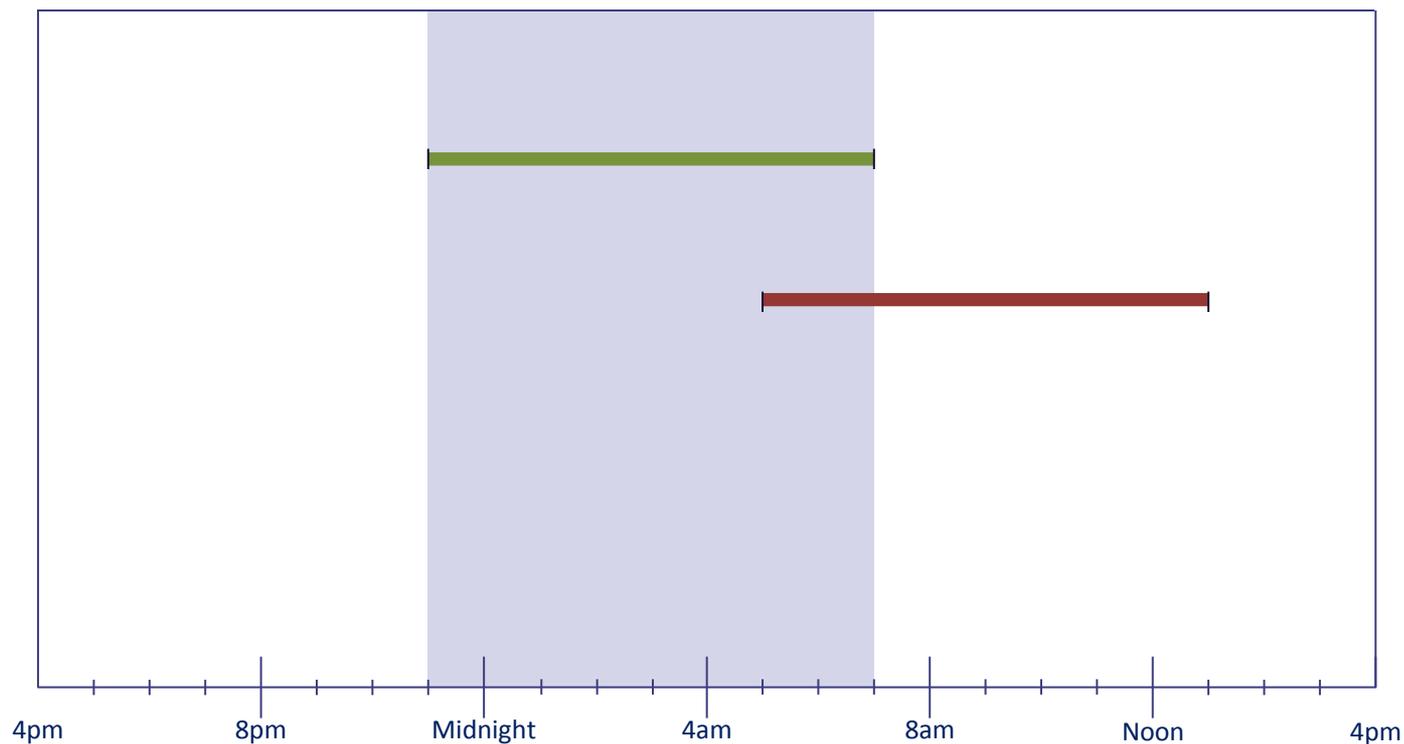
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Normal and Delayed Sleep Phases

Example of a Normal Sleep Phase

Example of a Delayed Sleep Phase





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Circadian Rhythm Sleep Disorders – TWO Factors

- Not entrained to day/night cycle
- Inflexible
 - This is the part people don't understand



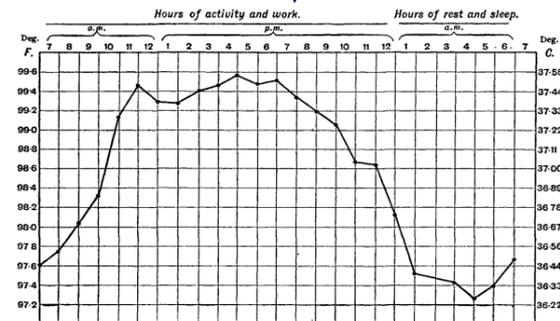
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Biological Markers

- Melatonin level (timing)
 - DLMO (Dim Light Melatonin Onset)
- Core body temperature
- Cortisol level





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Snooze Alarm



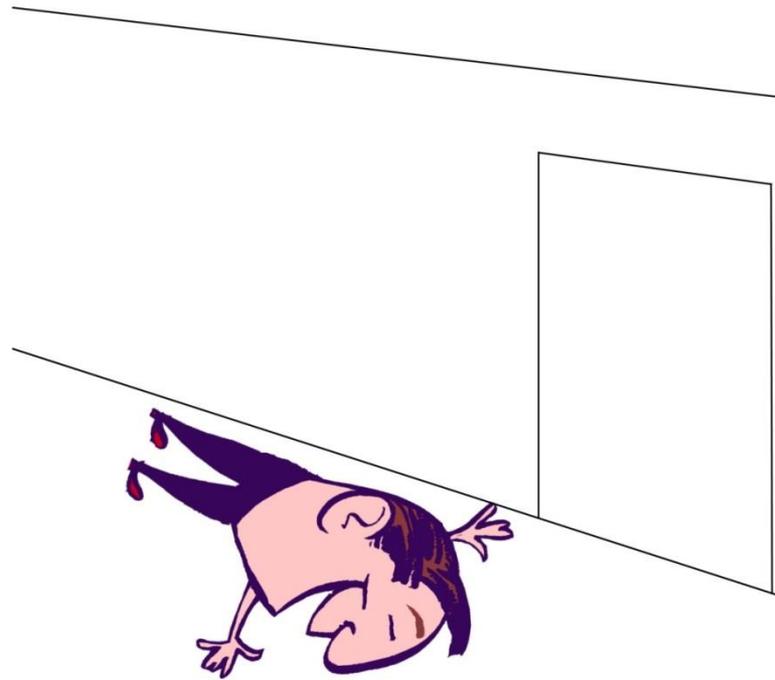


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Sleeping in Hallway





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Sleep Study

(not me)





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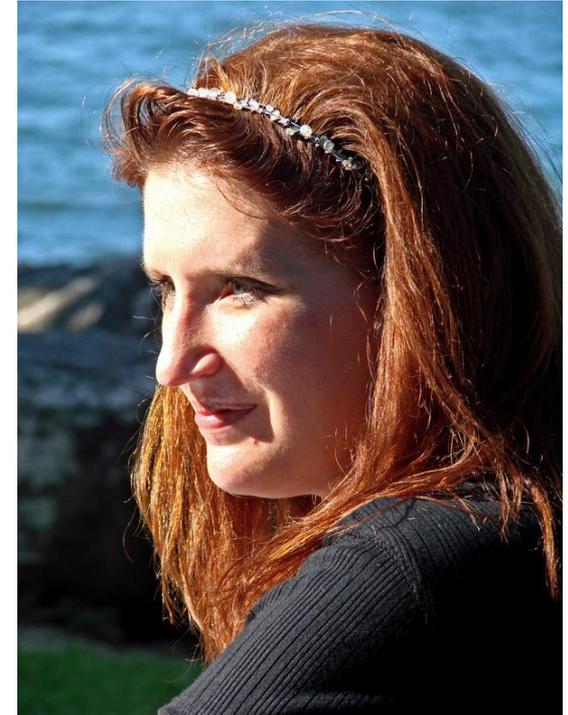
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Member Quote

“For decades I worked day jobs after sleeping 3:30 to 7:30 a.m., catching up on weekends.... That worked as long as youthful resilience lasted. Next step was adding a "nap" 5 to 10 p.m. Wreaks havoc with the social life, but it kept me my job for years.

“If you can't be normal, you're not good enough. You learn to apologize, make excuses, tell lies. No one understands.... “





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Member Quote



"I just can't help thinking that I'd have no problem being awake and alert if I were to simply follow my own natural sleep cycle. The only problems I would face are unemployment and nearly no social life."

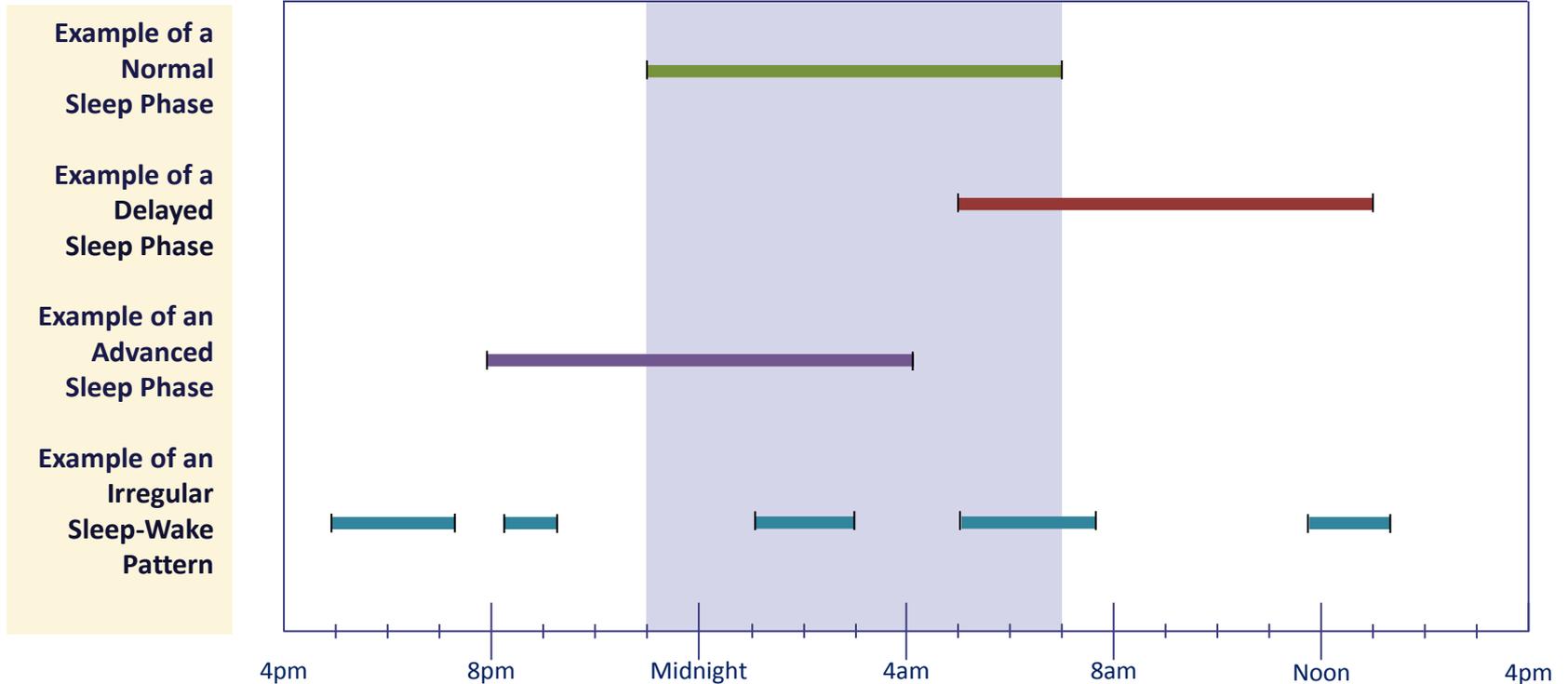


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Circadian Sleep Disorders Sleep Periods



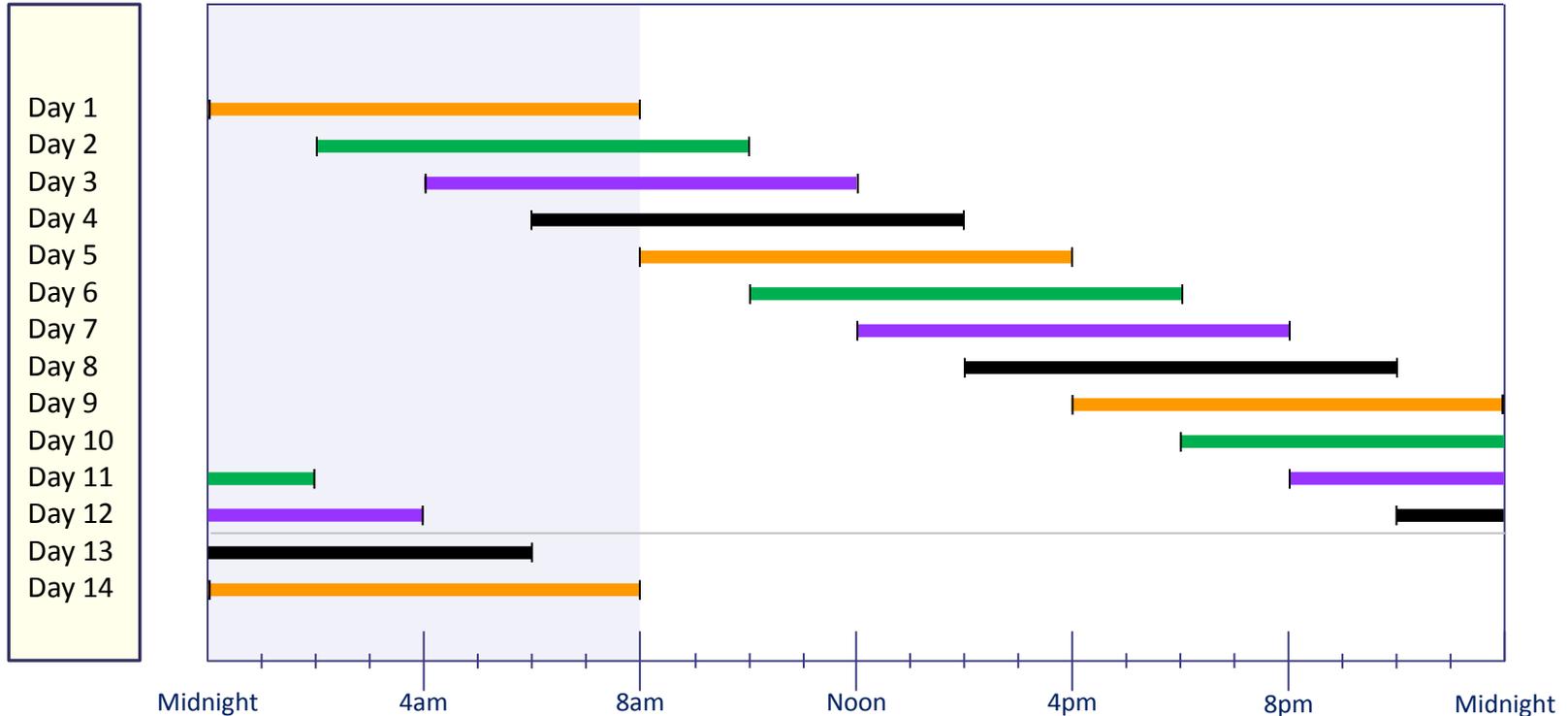


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Non-24-Hour Sleep-Wake Disorder Example of Progression of Sleep Periods





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Member Quote

“It's so frustrating not to be able to predict even one day in advance when I will be awake. Sure there is an overall vague 26-28 hour rhythm; but superimposed on that is this huge random element. Sudden unexpected bouts of insomnia at a time I thought I would sleep. Sudden overwhelming tiredness when I thought I would be awake. Everything is out of sync. ***My body is like an orchestra out of tune and with no conductor.***”





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Member Quote



“Ever since I became Non-24, I constantly have to beg people to change their schedules, or try to be pleasing and unobtrusive while I quietly ask if they have another time available. It's affected my relationships with all: family, who don't believe it in it; friends, who can never find a slot to talk to me, let alone get together, and have all finally stopped trying; doctors, next to impossible to schedule.... When I can't meet the world's demands, I am deemed selfish or weak or lazy or depressed.... I am fine with me. But the world is not fine with me, and that makes me not fine.

“I feel so isolated. I am desperate for social contact.”



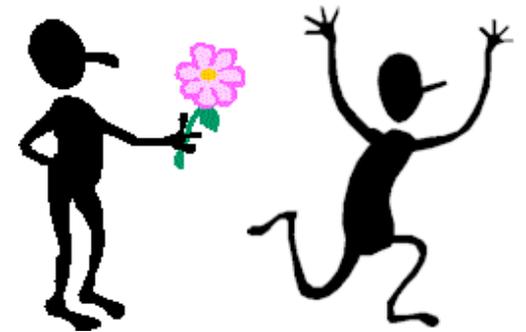
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Member Quote

"What is hardest is explaining non-24 to new acquaintances, for example someone you might meet at a party. It tends to derail the whole social process. The inability to remain employed has an even more profound effect on my social life. It's not something people accept when you look healthy."





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Incidence

Sleep Disorder	Number of Americans	Number of Americans
Narcolepsy	150,000	
Delayed Sleep Phase Syndrome (Adults)	500,000	
Delayed Sleep Phase Syndrome (Teens)	2,000,000	
Non-24-Hour Sleep-Wake Disorder	75,000	

 represents 75,000 Americans



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Possible Causes

- Lack of sensitivity to light
- Oversensitivity to light
- Long intrinsic circadian period
- Lack of melatonin
- Long elimination time of melatonin
- Deficiencies in ipRGC cells
- Longer time from temperature minimum to waking
- Difference in tolerance to phase mismatch



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Treatments

- Sleeping pills (no help) 
- Chronotherapy (risky) 
- Light therapy - in the morning 
- Light restriction (“dark therapy”) in the evening 
- Melatonin 



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Research Issues

- Different underlying causes
 - Tailoring therapy to cause
- Therapy parameters
 - Testing on patients, not normal sleepers
 - Long term and subjective improvement
- Better diagnostic tests
- Incidence data





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Circadian Sleep Disorders and Narcolepsy

- Common theme of daytime sleepiness
- Common experiences
- No good night's sleep – even with treatment
- Lots of PWNs are evening types
 - Possible co-morbid conditions?
- Possible misdiagnosis???
 - Shift workers test positive on MSLT



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Mission Statement

Circadian Sleep Disorders Network is a nonprofit organization dedicated to improving the lives of people with chronic circadian rhythm disorders.

We aim to increase awareness within the medical community and among the general public, to provide emotional support and practical ideas for people living with these disorders, to encourage research into circadian rhythms, and to advocate for accommodations in education and employment for people with circadian rhythm sleep disorders.



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Circadian Sleep Disorders Network

- Need
- Mission
- Goals – awareness, accommodation, research, support
- Issues
 - Sleep not taken seriously
 - Sleep disorders not taken seriously
 - Circadian Rhythm Sleep Disorders not widely known
- Awareness projects
- Things are starting to change



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CSD-N Awareness Efforts

- Created web site – lots of information – csd-n.org
- Published brochures
- Started Facebook and LinkedIn pages
- Arranged for other web sites to link to us
- Asked members to give brochures to doctors
- Arranged publication of articles on Salary.com
- Non-24 listed with NORD
- Supported Sleep Walk DC
- Spoke at NIH, NSART
- Provided CSD-N T-shirts, mugs, bumper stickers



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Thank You!

Visit us at: CircadianSleepDisorders.org

shortcut: csd-n.org

(don't forget the hyphen!)

Email me at: peter@csd-n.org