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
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)
Circadian Rhythm Sleep Disorders

- Definition
- Complaints
  - Insomnia
  - Excessive daytime sleepiness
- Coordination with other circadian rhythms
- Inflexibility
Circadian Sleep Disorders Network
Advocating for people with misaligned body clocks
csd-n.org

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)
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.
Normal and Delayed Sleep Phases

Example of a Normal Sleep Phase

Example of a Delayed Sleep Phase
Circadian Rhythm Sleep Disorders – TWO Factors

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

- Melatonin level (timing)
  - DLMO (Dim Light Melatonin Onset)
- Core body temperature
- Cortisol level
Snooze Alarm
Sleeping in Hallway
Sleep Study
(not me)
“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.... “
"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."
Circadian Sleep Disorders

Sleep Periods

Example of a Normal Sleep Phase
Example of a Delayed Sleep Phase
Example of an Advanced Sleep Phase
Example of an Irregular Sleep-Wake Pattern
Non-24-Hour Sleep-Wake Disorder
Example of Progression of Sleep Periods
“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.*"
“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.”
"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."
# Incidence

<table>
<thead>
<tr>
<th>Sleep Disorder</th>
<th>Number of Americans</th>
<th>Number of Americans</th>
</tr>
</thead>
<tbody>
<tr>
<td>Narcolepsy</td>
<td>150,000</td>
<td></td>
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<tr>
<td>Delayed Sleep Phase Syndrome (Adults)</td>
<td>500,000</td>
<td></td>
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<tr>
<td>Delayed Sleep Phase Syndrome (Teens)</td>
<td>2,000,000</td>
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<tr>
<td>Non-24-Hour Sleep-Wake Disorder</td>
<td>75,000</td>
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</tbody>
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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
Treatments

• Sleeping pills (no help)

• Chronotherapy (risky)

• Light therapy - in the morning

• Light restriction ("dark therapy") in the evening

• Melatonin
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
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
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.
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
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
Thank You!

Visit us at: CircadianSleepDisorders.org

shortcut: csd-n.org

(don't forget the hyphen!)

Email me at: peter@csd-n.org